Understanding Barriers and Facilitators to Dementia Risk Reduction behaviours among Indian Populations in the United Kingdom: A Thematic Analysis

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

Despite their status as the largest ethnic minority in the United Kingdom, the healthcare needs and experiences of South Asian people remain largely under-researched and inadequately understood (Prinjha *et al.,* 2020). This thesis aims to investigate the experiences of South Asian individuals in the United Kingdom with regard to palliative care services, as well as identifying barriers and facilitators to dementia risk reduction behaviours amongst Indian populations, thereby contributing to the limited bodies of literature on these subjects.

Part 1 presents a systematic review of the qualitative literature on the experiences of South Asian people, their carers, and staff members in the United Kingdom regarding palliative care services. The final review included a total of sixteen published studies. Findings suggested that key challenges faced by this population include limited awareness about available palliative care support, language and cultural barriers hindering open communication with healthcare staff, and a lack of integration of religious and cultural practices within caregiving approaches. Additionally, the review highlighted pervasive stigma surrounding discussions about death and end-of-life care within South Asian communities. Further research is needed to explore the nuanced needs of this population and to develop culturally appropriate interventions.

In Part 2, a qualitative investigation was conducted on the perspectives of cognitively healthy Indian adults in the United Kingdom regarding the barriers and facilitators related to engaging in lifestyle factors that may influence dementia risk. A thematic analysis identified three main themes: 1. Navigating the Complexities of Dementia Awareness and

Discourse in South Asian Communities 2. Determinants of Healthy Lifestyle Engagement: Personal and Contextual Factors Influences on Lifestyle Choices, and 3. Diverse Perspectives on Health: Accessing Medical Relationships and Other Information Sources. The findings underscore the need for culturally tailored education initiatives and support services to promote dementia risk reduction within this community.

Part 3 contains a critical appraisal, highlighting the interplay between the researcher and the research process, as well as offering further reflections on methodological choices and the resolution of challenges encountered during the study.

Impact Statement

The systematic review conducted in this thesis was the first qualitative synthesis of its kind examining the unique perspectives of South Asian people regarding palliative care services in the United Kingdom. This review has significant implications for research, clinical practice, and policy, by highlighting the multifaceted barriers this population faces in accessing and effectively using palliative care services. The review identified several key challenges: limited awareness of available support, language and cultural barriers hindering open communication with healthcare providers, and the lack of integration of religious and cultural practices within existing caregiving approaches. A notable finding was the stigma surrounding discussions about death and end-of-life care within South Asian communities, which posed a significant obstacle to open dialogue and the recognition of palliative care needs.

Additionally, the review highlighted the need to bridge the gap between cultural beliefs and practices surrounding death and dying and our mainstream healthcare system's approach to palliative care. The disconnect between these perspectives often resulted in a lack of culturally sensitive and inclusive services, deterring some South Asian individuals and their families from seeking or accepting support during this critical life phase. The findings emphasize the need for targeted interventions, such as community engagement initiatives, improved language services, and fostering cultural humility among healthcare professionals, to ensure South Asian individuals can access culturally competent and compassionate end-of-life care.

In addition to the systematic review, an empirical study involving interviews with Indian participants explored barriers and facilitators to engaging in positive lifestyle behaviours for dementia risk reduction. This study found a lack of awareness about dementia as a distinct condition from normal aging, particularly amongst older adults. Stigma surrounding dementia further hindered open conversations about the condition and the seeking of advice or support. Language barriers, especially for older adults with limited English proficiency, restricted access to information and support resources about dementia and healthy lifestyle practices. Prevailing gender norms and caregiving responsibilities impacted some people’s ability to prioritize activities like exercise and nutritious diets. Economic constraints also posed barriers for some participants regarding lifestyle changes like healthier diets. Some participants, particularly younger adults, were open to learning more about dementia risk reduction from trusted community figures and sources, with culturally tailored messaging viewed as more effective than generic health resources.

In terms of dissemination, the thesis's main findings will be shared with local community organizations and healthcare providers serving South Asian populations. Additionally, a report detailing the empirical study results will be sent to participants who expressed an interest in receiving a copy. To further extend the impact of this research, both the systematic review and empirical study will be submitted for publication, aiming to contribute to research, inform awareness campaigns, and guide policy development.

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Acknowledgements

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Part 1: A systematic literature review exploring experiences of palliative care provision for South Asians in the United Kingdom

Abstract

Aims: This review aimed to explore the experiences and needs of South Asian patients of end of life and palliative care services, and their carers, in the United Kingdom. It also incorporated the perspectives of staff members working with this population. It is the first study to identify, evaluate and synthesize qualitative literature on how South Asian adults in the United Kingdom experience palliative care services.

Method: Three databases (PsycINFO, MEDLINE, and Scopus) were systematically searched for qualitative research in this area on August 4th, 2023. Papers were screened and sixteen articles were included in the final synthesis. The articles underwent a quality evaluation process, and the information extracted was synthesized and incorporated into a thematic meta-synthesis.

Results: Sixteen studies involving 407 patients, caregivers, and staff members were included. The themes identified were: barriers and facilitators to discussing and preparing for end of life; the impact of identity and culture on end-of-life practices and rituals; family roles and expectations regarding palliative care, and navigating challenges across care settings and healthcare interactions.

Conclusions: This review provides valuable insights into the experiences of South Asian individuals, caregivers, and healthcare professionals within palliative care settings in the United Kingdom. The identified themes highlighted multifaceted challenges, emphasizing the need for culturally sensitive and inclusive palliative care services. Barriers hindering

access to care including linguistic challenges, lack of awareness, and cultural insensitivity, underscore the necessity for targeted interventions and improved cultural humility among healthcare providers. Addressing these gaps could significantly enhance the quality and inclusivity of palliative care services for South Asian populations.

Introduction

Minority ethnic communities in Western countries, including South Asian individuals, often face challenges accessing palliative care services (Worth *et al.,* 2009; Seymour *et al.,* 2007). South Asian people constitute the largest ethnic minority group in the United Kingdom (Office for National Statistics, 2022). Globally, research has highlighted the heightened prevalence of some life-threatening and chronic diseases among South Asian migrants compared to other ethnic groups (Shabnam *et al.,* 2020). To enhance healthcare for individuals in marginalized social positions, it is crucial to comprehend how healthcare systems intersect with their experiences (Fang *et al.,* 2016).

Palliative care services endeavour to provide holistic care and to enhance quality of life for individuals facing advanced illness or nearing the end of life, along with providing support to their families. This is accomplished by effectively managing pain and other distressing symptoms, alongside providing psychological, social, and spiritual support (National Council for Hospice and Specialist Palliative Care Services, 2002). Unfortunately, inequities in provision have persisted in palliative care services (Dixon *et al.,* 2015, Care Quality Commission, 2016). The Care Quality Commission in their 2016 report stated that people from minority ethnic groups faced ongoing inequalities in palliative care, particularly those with diagnoses other than cancer, and older adults. The report highlighted that people from minority ethnic backgrounds struggled with being able to access the right care at the appropriate time, with some patients not identified early enough, while poor communication and a lack of individualized care prevented others from receiving good end of life care. The report emphasized that individuals from diverse equality groups often do not receive optimum end of life care. Among patients requiring palliative care, those of Black, Asian, and minority ethnic backgrounds tend to receive referrals at a more advanced stage of their condition relative to white patients, a disparity which intensified during the COVID-19 pandemic (Chidiac *et al.,* 2020).

While some evidence suggests that individuals from Black, Asian, and minority ethnic ("BAME") backgrounds, especially immigrants, are more likely to die in a hospital setting rather than at home or in a hospice compared to other patient groups (Care Quality Commission, 2016), another recent analysis based on the National Survey of Bereaved People in England (2015) presented different results, finding that individuals from BAME backgrounds did not demonstrate a greater or lesser tendency than those of white ethnicity to die in hospitals rather than at home. However, individuals from BAME communities were less inclined to rate the overall care received during the final three months of life as "outstanding" or "excellent". Further research is needed to better understand the reasons for this (Dixon *et al.*, 2015). Several barriers for ethnic minority groups at end of life have been identified, including cultural insensitivity in information dissemination, a lack of awareness of palliative care services among some minority ethnic people, a lack of trust in healthcare systems, language barriers impeding communication and access, and experiences of racism (Philips & Taylor, 2012; Age UK, 2021).

Calanzani *et al.,* (2013) noted in their review that while preferences influenced by cultural or religious factors may be very relevant for some people at end of life, these cannot be automatically assumed solely based on ethnic backgrounds and will significantly vary among individuals. Preferences linked to specific cultural or religious practices are also likely to evolve over time, as subsequent generations may adopt attitudes and values more aligned with other British-born groups. The authors noted the scarcity of studies attempting to explore how individuals facing advanced illness define their own cultural requirements. The significant influx of South Asian immigrants to the United Kingdom began post-World War II, with substantial waves in the 1950s, 1960s, and 1970s (Burholt *et al.,* 2002). Many individuals who migrated during these initial phases are now entering their elderly years, a phase where demand for palliative care services escalates.

Understanding and addressing the cultural, social, and healthcare requirements of South Asians is crucial to ensure the adequate and culturally sensitive delivery of palliative care services. The aim of this review, therefore, is to explore the experiences and needs of South Asian patients and their carers regarding end-of-life and palliative care services in the United Kingdom, while also incorporating the perspectives of healthcare staff working in these services. The “PCC” (Population, Concept, Context) framework was utilized to structure the research question and guide the review process (Peters *et al.,* 2020). The population was South Asian patients (aged 18+), caregivers, and staff members; the concept was experiences, needs, and psychosocial perspectives on palliative and end-of-life care; and the context was the United Kingdom.

Methods

An examination of the available qualitative research exploring psychosocial aspects of palliative care for South Asian individuals in the United Kingdom was conducted. The review adhered to the Cochrane guidelines for Qualitative Evidence Synthesis (Noyes *et al.,* 2023). The findings from relevant literature over the past two decades were synthesized thematically (Thomas & Harden, 2008). Thomas and Harden (2008) integrated elements from both meta-ethnography and grounded theory to develop their approach to thematic synthesis. This method emerged from the need to conduct reviews that address questions about the necessity, suitability, and acceptability of interventions, while still adhering to the key principles of systematic reviews (Barnett-Page & Thomas, 2009). Prior to initiating the review, a protocol was completed and registered online (PROSPERO registration number: CRD42023442603). The reporting of findings adheres to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page *et al.,* 2021).

Epistemology

The epistemological stance of thematic synthesis, though involving interpretation of data, generally presents a less contentious view of reality when compared with methodologies like critical interpretive synthesis. Thematic synthesis operates under the assumption that its findings are replicable and indicative of a collective reality, especially given its intended application in shaping policy and practice (Barnett-Page &Thomas, 2009). At the same time, thematic synthesis acknowledges the nuanced nature of reality and can be categorized as adopting a critical realist perspective (Barnett-Page &Thomas, 2009). This perspective recognizes the complexity inherent in reality, while also asserting that there are underlying structures and mechanisms that can be understood to a certain extent (Marks & O'Mahoney, 2014).

Data Sources and Searches

Appendix 1, available as supplementary material, outlines the search strategies employed. The searches took place in the Ovid database across MEDLINE, PsycINFO, and SCOPUS. Additionally, the Web of Science database was accessed solely to perform forward citation searching on all articles included in the final synthesis. To uncover further relevant literature, reference lists within all studies included in full-text screening were also examined. An iterative approach was adopted, exploring all available concepts until saturation was achieved. Following the guidance by Tong *et al.* (2012) on reporting qualitative research, relevant websites, Google Scholar, and consultation with a librarian were also utilized to locate additional pertinent studies.

Selection Criteria

The following inclusion and exclusion criteria were applied to select relevant studies for this review:

Inclusion criteria

1. Qualitative studies exploring experiences of South Asian patients aged 18+, caregivers, and staff members working in these contexts
2. Focus on end-of-life care contexts (palliative care, advanced care planning, end-of-life care)
3. Studies conducted within the United Kingdom
4. Empirical, peer-reviewed studies

5. Studies using entirely qualitative or mixed methods approaches (with only qualitative components included in synthesis)
6. Studies published between August 2003 and August 2023 to ensure results reflected current policies, research, and service provision. For instance, the timeframe encompasses key developments such as the Department of Health's review of palliative care for Black, Asian, and Minority Ethnic Groups (Calanzani *et al.,* 2013), NICE guidelines on end-of-life care (NICE, 2019), and the NHS's framework for palliative care (National Health Service, 2021).

Exclusion criteria

1. Studies focusing on palliative care or end of life services for South Asian children
2. Studies conducted outside the United Kingdom
3. Non-empirical or non-peer-reviewed studies
4. Studies using solely quantitative methods
5. Studies published before August 2003 or after August 2023.

Data Extraction

The databases were searched and de-duplicated using EndNote software. Title and abstract searches were conducted to identify studies for full text inspection, using the predefined inclusion and exclusion criteria. The author/s, year, aims, setting, population, age, ethnicity, recruitment method, analyses method, data analysis, and main results were extracted from each study. Extracted data was recorded on an excel spreadsheet. Another reviewer independently double rated 10% of the hits, with disagreements resolved through discussion. All studies identified for full text inspection were rated by the author, with another reviewer double rating 10% of the hits. There was 100% agreement between the two reviewers. Studies were included at the full text screen stage if they met the inclusion criteria for the current review. Subsequently, the full texts of the remaining papers were screened, and the reasons for exclusion were documented for each case.

Quality Assessment

The quality evaluation process employed the Critical Appraisal Skills Programme Checklist (CASP, 2018, Appendix 2) for assessing qualitative research. This tool, consisting of ten questions that address various methodological aspects of qualitative research, is endorsed by the Cochrane Qualitative and Implementation Methods Group (Noyes *et al.,* 2018). Each paper's quality rating was determined based on the proportion of criteria met. For mixed methods studies, only the qualitative components were evaluated. Although the CASP Checklist does not provide a specific scoring system, a score was calculated for each study according to the number of responses reported as "yes." Studies were classified as high quality (scores of 8-10), medium quality (scores of 5 -7), or low quality (scores of 0-4) (Long *et al.,* 2020). Tong *et al's* (2012) guidance was also followed, suggesting that one can consider and employ established frameworks for reporting qualitative research as a foundational basis, adapting them to align with the synthesis topic. The selected framework should encompass the methods and methodologies employed in the studies included in the synthesis. These additional aspects of each study were noted and outlined in Table 1.

Data Analysis

Following this stage, the qualitative components from each paper were analysed in accordance with established guidelines for thematic synthesis (Lachal *et al.,* 2017; Thomas & Harden, 2008). Thematic synthesis, which integrates thematic analysis, a widely used approach developed by Braun and Clarke (2006; 2022), is specifically designed for synthesizing qualitative research. Thomas and Harden's (2008) approach to thematic synthesis involves several key stages. Initially, the findings from each study are coded line-by-line to identify key concepts and themes in the data. These initial codes are then organized into broader descriptive themes, grouping similar codes together to form patterns that describe the data. Finally, the descriptive themes are synthesized into analytical themes, where reviewers interpret the data to generate new insights beyond the original findings. Following the recommendations of Thomas and Harden (2008), an inductive approach was adopted for data analysis, deriving insights directly from the data itself rather than imposing pre-existing codes or attempting to address predetermined research inquiries.

The process began by becoming familiar with the data. Quotations from participants from all sections of each article were imported into NVIVO for analysis. A line-by-line coding of the studies' findings was performed, allowing for the conceptualization of the data and the inductive identification of concepts. For subsequent articles, text was either sorted into existing codes or new codes were created as necessary. Similar codes were then clustered into themes and subthemes. To expand on the findings of the primary studies, conceptual links among themes were identified. The initial codes were then synthesized to generate comprehensive themes. Digital copies of the original research papers served as the primary data sources. Following the guidelines produced by Thomas and Harden (2008) all sections labelled “results”, “findings”, or “discussion” in the papers were coded. The texts were imported into NVivo (QSR International Pty Ltd., 2020), a qualitative data analysis software, to facilitate the synthesis.

Long *et al.* (2020) proposed an innovative approach to guide researchers' synthesis strategies, which was followed for this synthesis. Building upon Thomas and Harden's (2008) methodology for qualitative synthesis, they advocated that studies rated as higher quality should hold greater weight in the synthesis. Therefore, in the present study, higher quality studies were initially coded, allowing them to form the foundation of the coding framework and to potentially influence the study’s overall findings more heavily.

Initially, all sixteen papers were reviewed to establish familiarity with the data and initiate the identification of potential codes. Following this, an inductive line-by-line coding process was employed on the data extracted from the papers recognized as high quality, focusing on all data pertinent to the research question. The primary aim was to code first-order data, specifically direct quotations from participants, wherever feasible. Subsequently, second-order data, encompassing the words and interpretations provided by the authors of the studies, were coded. It is important to note that not all text received codes, especially in cases where studies contained information not relevant to the study at hand.

Next, the studies of medium quality were reviewed, utilizing the existing codes and introducing new ones where appropriate. These codes were then applied to the papers that had been previously coded. The initial set of codes was scrutinized, and the codes were formulated into descriptive themes. Subsequently, analytical themes were developed, aligning with Thomas and Harden's (2008) description of this stage as the point where reviewers surpass the primary studies to formulate new interpretive constructs, explanations, or hypotheses.

Results

Literature Search

The search yielded 366 articles. Of these, 295 were screened out at the title and abstract screening stage. 43 articles were screened fully and 16 met inclusion criteria for the current study.

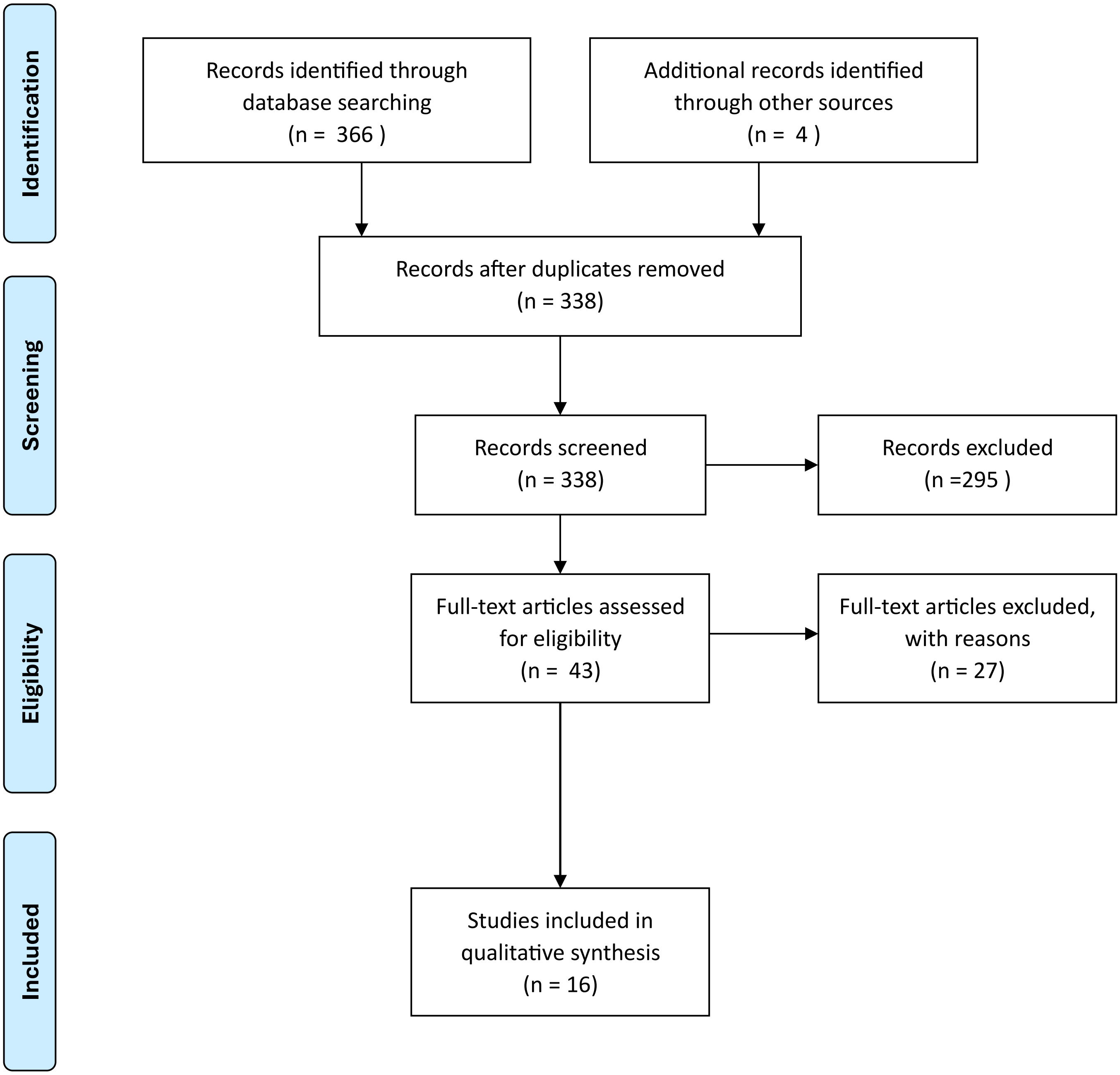

Figure 1: Prisma flowchart

Study characteristics

All studies were of medium (n=5) or high (n=11) quality (Table 1). The comprehensiveness of reporting was mixed. All studies involving patients and/or carers provided some description of the participant's demographic characteristics, but the level of description was variable, with some studies only stating that patients were South Asian, or describing them only by their religion, rather than breaking this down into more specific ethnicities. This was the case in nine studies (56%), excluding two studies solely focusing on staff perspectives. Demographic information was only provided in one study involving healthcare professionals as participants.

Four of the sixteen studies (25%) used a participatory approach to some extent, with one study consulting a patient advisory group to inform the topic guide and preliminary findings (Hossain *et al.,* 2022), one consulting a steering group comprised of palliative care professionals and representatives from Luton Health Action Zone (Owens & Randhawa, 2004), the third study consulting with palliative care practitioners and a project steering group to devise the question schedule (Randhawa *et al.,* 2003), and the fourth study stating that Public and Patient Involvement representatives from British South Asian communities were consulted for guidance (Clarke *et al,* 2023). Interview schedules were shared in five (31%) studies, and examples of the coding process was shared in two studies (12.5%). It is important to note that three studies (Venkatasalu 2017, Venkatasalu *et al.,* 2013, and Venkatasalu *et al.,* 2014) drew on concurrently collected data as part of an exploration of the same participant groups. As a result, there was overlap in participants between these studies. Accounting for this, a total of 407 patients, caregivers, and professionals participated in the qualitative components of these studies.

In terms of the types of methodology employed, four used thematic analysis, three used constructive grounded theory, two used action research design, two used Interpretative Phenomenological Analysis ("IPA"), two described analysing data in a "similar manner to the technique of O'Brien (1993)", one described a "coding technique similar to that described by Denzin & Lincoln (1997)", one was informed by Mattingly's theory on hope, and one used a qualitative "hybrid methodology" encompassing clinical practice and law.

Table 1:
Summary of Studies

Author/s	Title	Year	Number of participants	Ethnicity, sex, and age of participants if reported	Study setting	Type of analysis	Interview schedule shared	Examples of coding/ transcript	Quality Rating (CASP)
Clarke, G. Crooks, J. Bennett, M. I. Mirza, Z. Bhatti, R. (OBE) Nazar, W. Mughal, R. & Ahmed, S.	Experiences of pain and pain management in advanced disease and serious illness for people from South Asian communities in Leeds and Bradford: a qualitative interview study.	2023	15 patients and carers	Ages:18-90. Sex: 9 female, 6 male. Religion: 12 Muslim, 3 Sikh.	Leeds and Bradford	Reflective thematic analysis	Yes	No	High
Cowan, M.	The lived experiences of the Sikh population of Southeast England when caring for a dying relative at home.	2014	6	Ages: 31-70. Sex: 6 females Religion: All Sikh.	Dartford and Gravesham	Interpretative phenomenology	No	No	Medium
Gaveras, E. M. Kristiansen, M. Worth, A. Irshad, T. & Sheikh, A.	Social support for South Asian Muslim parents with life-limiting illness living in Scotland: A multiperspective qualitative study.	2014	8 patients, 6 carers, and 9 health professionals	Ages: parents with children under the age of 18 Sex: 4 males, 4 females (patients) Religion: All Muslims.	Scotland	Interpretative Phenomenological Analysis (secondary data analysis)	No	No	High
Hossain, M. Z. Tarafdar, S. A. Kingstone, T. Campbell, P. & Chew-Graham, C. A.	From detection to preparing for the end-of-life: A qualitative exploration of the South Asian family carers' experiences of the journey with dementia.	2022	16	Ages: from 20-80. Sex: Male: 9, Female: 7. Ethnicity: Indian: 9 Bangladeshi: 6 Pakistani: 1 Religion: Muslim: 10 Sikh: 4 Hindu: 1 Christian: 1	West Midlands	Thematic analysis using the principles of constant comparison, adopting interpretivist-constructionist theory	No	No	High
Kristiansen, M. Irshad, T. Worth, A. Bhopal, R. Lawton, J. & Sheikh, A.	The practice of hope: a longitudinal, multi-perspective qualitative study among South Asian Sikhs and Muslims with life-limiting illness in Scotland.	2014	25 participants, 15 family members and 20 health care professionals	Sex: 13 males, 12 females (from the patients). Ethnicity: South Asian Sikhs and Muslims	Scotland	Analysis was informed by Mattingly's theory on hope	Yes	No	High
Moss, R. H. Hussain, J. Islam, S. Small, N. & Dickerson, J.	Applying the Community Readiness Model to Identify and Address Inequity in End-of-Life Care in South Asian Communities.	2023	10 (staff/stakeholders, focus group)	Not known.	Bradford	Reflexive thematic analysis	Yes	No	Medium
Owens, A., & Randhawa, G.	It's different from my culture; they're very different': Providing community-based, 'culturally competent' palliative care for South Asian people in the UK.	2004	10 (staff)	Not known.	Luton	Coding technique similar to that described by Denzin & Lincoln (1997)	No	No	Medium
Randhawa, G., & Owens, A.	The meanings of cancer and perceptions of cancer services among South Asians in Luton, UK.	2004	48 (focus groups)	Ages: 18-60 Ethnicity: Pakistani Punjabi, Bangladeshi Sylheti and Indian Punjabi.	Luton	A coding technique similar to that described by O'Brien" (1993)	No	Yes	High
Randhawa, G., Owens, A., Fitches, R., & Khan, Z.	Communication in the development of culturally competent palliative care services in the UK: A case study.	2003	12 adults (2 patients, 10 family members) and 10 staff members	Ages: 18-60 Religion: four Muslim families, one Hindu family.	Luton	"A coding technique similar to that described by O'Brien" (1993)	Main themes for questions shared	Yes	High
Samanta, J., Samanta, A., & Madhloom, O.	A rights-based proposal for managing faith-based values and expectations of	2018	12	Ages: 28 - 72 years.	Leicester	Qualitative focus groups; encompassing the	No	No	Medium

	migrants at end-of-life illustrated by an empirical study involving South Asians in the UK.			Sex: 6 males and 6 females. Religion: 7 Hindus, 5 Muslims.		transdisciplinary arc of clinical practice and law			
Venkatasalu, M. R.	Let him not be alone: perspectives of older British South Asian minority ethnic patients on dying in acute hospitals.	2017	Five focus groups and 29 interviews, with a total of 55 participants	Ages 50+ Sex: 15 males, 19 females. Ethnicity: 10 Bangladeshi, 19 Indians, 2 Pakistanis, 3 Sri Lankans;	East London	Constructive grounded theory	No	No	Medium
Venkatasalu, M. R., Arthur, A., & Seymour, J.	Talking about end-of-life care: The perspectives of older South Asians living in East London.	2013	Five focus groups and 29 interviews, with a total of 55 participants	Ages: 50+; Sex: 15 males, 19 females. Ethnicity: 10 Bangladeshi, 19 Indians, 2 Pakistanis, 3 Sri Lankans;	East London	Constructive grounded theory	No	No	High
Venkatasalu, M. R., Seymour, J. E., & Arthur, A	Dying at home: A qualitative study of the perspectives of older South Asians living in the United Kingdom.	2014	Five focus groups and 29 interviews, with a total of 55 participants	Ages: 50+ Sex: 15 males, 19 females. Ethnicity: 10 Bangladeshi, 19 Indians, 2 Pakistanis, 3 Sri Lankans;	East London	Constructive grounded theory	No	No	High
Wilkinson, E. Randhawa, G. Brown, E. A. Da Silva Gane, M. Stoves, J. Warwick, G. Akhtar, T. Magee, R. Sharman, S. & Farrington, K.	Communication as care at end of life: An emerging issue from an exploratory action research study of renal end-of-life care for ethnic minorities in the UK.	2014	16	Ages: 69-86 Sex: 8 males, 8 females Ethnicity: not described	West London, Luton, Leicester and Bradford	Action research design	No	No	High
Wilkinson, E., Randhawa, G., Brown, E., Da Silva Gane, M., Stoves, J., Warwick, G., Mir, T., & Magee, R.	Time, timing, talking and training: findings from an exploratory action research study to improve quality of end of life care for minority ethnic kidney patients.	2017	45 care providers (focus groups) and 16 patients (interviews)	Sex: 8 male, 8 female. Ethnicity: South Asian, not described further	West London, Luton, Leicester and Bradford.	Action research design	No	No	High
Worth, A. Irshad, T. Bhopal, R. Brown, D. Lawton, J. Grant, E. Murray, S. Kendall, M. Adam, J. Gardee, R. & Sheikh, A.	Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: Prospective longitudinal qualitative study.	2009	25 patients, 18 family carers, 20 health professionals	Mean age 59, Ethnicity: 25 South Asian Sikh and Muslim patients	Scotland	Thematic analysis	Yes	No	High

Thematic Synthesis

The synthesis incorporated the perspectives of patients, their family members, caregivers, and relevant professionals, aiming to provide a multi-faceted understanding of this population's experiences. In qualitative research, results typically comprise direct quotations from participants, coupled with the authors' analysis of the data. To maintain a clear distinction between these elements in the findings of this study, direct participant quotations are presented in italicized quotation marks, while the study authors' interpretations are presented within regular quotation marks. Each quotation is referenced to indicate its source paper. A summary of the themes and subthemes is shown below in Table 2.

Table 2:
Overview of themes and subthemes

Themes	Subthemes
1. Barriers and facilitators to discussing and preparing for end of life	1.1 Discussing death: patient and family perspectives
	1.2 Staff perspectives on end-of-life discussions
	1.3 Language barriers, use of interpreters and impact on care
2. The impact of identity and culture on end-of-life practices and rituals	2.1 The role of faith in end-of-life discussions and care
	2.2 Gendered Perspectives on end-of-life dynamics
3. Family roles and expectations regarding palliative care	3.1 Family as caregivers
	3.2 Roles and expectations of the new generation in end-of-life care
4. Navigating Challenges Across Care Settings and Healthcare Interactions	4.1 Lack of awareness of services
	4.2 Experiences with hospital and homecare services at end of life

Theme One: Barriers and facilitators to discussing and preparing for end of life

1.1 Discussing death: patient and family perspectives

End-of-life care is a complex area, encompassing a range of cultural, religious, and spiritual beliefs, emotional experiences, practical considerations, and diverse viewpoints. One barrier described by some participants when it came to accessing palliative care services was a perceived stigma around discussing death. The reasons for avoiding discussions about death among patients and families encompassed cultural norms, a belief that conversing about death might accelerate its arrival, and a sense among patients that their families would take charge of necessary arrangements or plans for their passing.

In one study, five participants explained how they typically sidestepped discussing death or completing a will due to stigma-related concerns (Hossain *et al.,* 2022). Among some Muslim participants, a prevalent belief existed that contemplating death might bring it closer and alarm others: "*I'm frightened, but who do I tell? If I let her know that I'm suffering so much, she (wife) may panic. So no one I can talk to but I can deal with that at the moment..."* (Wilkinson *et al.,* 2014). Participants from various South Asian backgrounds highlighted how talking about death or services which support people at end of life was not commonplace: *"As a society we don't talk about death, generally, in the same way that we will dedicate our time to preparing for the arrival of a new birth in the family or in the community..."* (Moss *et al.,* 2023).

Moreover, some participants discussed their resistance to discuss wills and advanced planning due to cultural stigmas linked to financial matters: "*They don't like to talk about the will, if the children say have you made, we need to make a will, they think that they want to take everything away from them (laughs)...*" (Hossain *et al.,* 2022). Participants' reticence to engage in discussions about death and dying was evident in instances where family members withheld information about terminal illness: "*We never told our father he had cancer. He was very ill first, few days how long he survived… He didn't know it. This is the last because there is no cure"* (Randhawa & Owens, 2004). Participants indicated that their families tried to shield them from the perceived distressing effects of talking about death. This attitude reflected a cultural norm where conversations regarding death and dying were considered taboo within many families, particularly in South Asian customs (Venkatasalu *et al.,* 2013). There were also exceptions to this, with some participants expressing their preferences for timely planning discussions and arrangements for funerals (Hossain *et al.,* 2022).

1.2 Staff perspectives on end-of-life discussions

Healthcare professionals, too, encounter apprehension when initiating conversations about death with patients and their families (Wilkinson, 2014). Many felt that their training had not adequately prepared them for these conversations. Their discomfort often arose from a fear of upsetting patients or their loved ones, leading to an inclination to avoid discussing the inevitable: *"I think sometimes there's just collusion between everybody and everybody knows but nobody actually wants to bring it into the air and have that discussion and upset people..."* (Wilkinson *et al.,* 2014). This emphasizes the discomfort among some healthcare providers in addressing end-of-life matters openly, suggesting that there might be an interplay between staff members and patient’s reluctance to discuss death, which become mutually reinforcing. Additionally, staff members might grapple with their own fears and anxieties associated with mortality, which can inadvertently affect the quality and depth of discussions about end-of-life care: "*That’s where I think we have the problem, if you feel that these conversations have to end in an 'end of life' discussion, then, of course, you’re going to avoid them*..." (Wilkinson *et al.,* 2014). This highlights how the fear of navigating complex, emotionally charged discussions might lead to avoidance by healthcare professionals. Providers also struggled with what was described as a lack of knowledge and training around how a good death would be for people from South Asian backgrounds: *“Because what does a good death look like, what is a good death from a South Asian patient point of view? We don’t know. All we know, what is a good death from a middle class, white Caucasian, . . . educated point of view”* (Moss *et al.,* 2023).

1.3 Language barriers, use of interpreters and impact on care

For patients with limited English, replying on external parties for linguistic support introduced layers of complexity in ensuring the accurate portrayal of information. Patients resorted to a variety of communication aids, such as seeking assistance from family members or neighbours, and using nonverbal signals: "...*they knew, because I went so often, that I couldn’t speak the language so they just pointed to machines and chairs and I understood*..." (Owens & Randhawa, 2004). In emergency situations, non-English-speaking patients faced heightened challenges in articulating their needs and understanding critical medical information. For some families, knowing that their loved one would struggle to communicate in a hospital or hospice setting introduced a barrier to care: *“My husband he cannot speak English, it’s very difficult, so if he was in somewhere where people cannot communicate with him, that would be difficult.”* (Owens & Randhawa, 2004). For patients with good conversational English, providers may not always realize when medical concepts are not fully understood, as noted by one family member: “*Mum and Dad’s English is good, like they can have conversation, but I think sometimes you know, when things get a bit technical, and there is that technically language there, it kind of baffles them, and they kind of go quiet*” (Clarke *et al.*, 2023).

The dynamics of using family members as translators involved a series of ethical and practical considerations. One provider's observation shed light on these challenges: "*I quite often found in the clinic that if a family member was there and was there to be an interpreter, then quite often you’d say, 'oh, could you ask your relative how they’re feeling about something?' And they’d answer on their behalf*..." (Wilkinson *et al.,* 2014). This raised questions about the authenticity of the conveyed language and whether the family member inadvertently became a filter for the patient's voice. Another provider reflected on this complexity, stating: *"...I sometimes felt I got the opinion of the relative rather than the patient"* (Wilkinson *et al.,* 2014). The dual role of family members as both advocates and interpreters introduced complexity in disentangling the patient's wishes from potential familial influences as well as having the potential to introduce errors in translation.

In Owens & Randhawa's (2004) study, healthcare professionals sometimes expressed discomfort with this reliance on family interpreters, while most patients indicated a preference for utilizing family members rather than engaging a professional interpreter. Patients and their families sometimes distrusted interpreters due to their belonging within the local community, and the risks to their privacy that could arise as a result. However, Wilkinson *et al.* (2014) did note some instances in which patients found value in using a bilingual support worker working alongside clinicians.

In Randhawa *et al's* (2003) study, some providers worried that the provision of interpreting services may be adding to emotional stress for carers, especially when it came to children: *"… I think children are used a lot of the time as translators and I think it's fairly upsetting, some of the things we have to ask, and they have to be there for the examinations, and I just think it's so unfair on the child. It's a big responsibility, they don't always understand what's going on, and there's a lot of time when, if you've got a child translating for you – usually it's the women who need the translators more than the men – a lot of the emotional stuff they are not going to express to their child to hear, because they're trying to protect their children as well."*

However, not all interviewees saw the use of family interpreters as being inherently negative. While recognizing the potential issue of selective interpretation, some staff participants highlighted the benefits of involving family members as translators, especially when conveying distressing information: *"Often you've got family members and they know how actually to support them because they know how they're going to react; they would* *know how they would want to be told. So in fact by using a family member you have an understanding of their personality and maybe some of the bad news that goes with it, part of the family history, there may be another member of the family who died of a similar illness... they have a relationship with them and they have an understanding how they tick".*

Using family interpreters in healthcare presented complexities and questions about the emotional impact for family members and children, and the accuracy of the portrayed information. At the same time, many patients and some staff members felt that family members were well placed to sensitively convey information to their loved ones and that a better option within current systems did not exist.

Theme Two: The impact of identity and culture on end-of-life practices and rituals

2.1 The role of faith in end-of-life discussions and care

Participants spoke about how religion can instil hope, how emotional support could be provided through religious practices, as well as challenges and barriers which arose when trying to practice one's faith in a hospital setting at end of life. Participants' narratives highlighted the often-profound role of faith in sustaining hope amidst terminal illness. A Sikh woman summarized this synergy between faith and medical treatment: *"We believe that taking medication and praying to God to help towards cure"* (Kristiansen *et al.,* 2014). However, the burden of maintaining hope, particularly within the Muslim community, surfaced as a significant challenge. The pressure to remain optimistic despite poor prognoses silenced some participants' desires for relief through death, with one author noting: "At times, however, the expectations on participants to remain hopeful despite their poor prognosis and immense suffering put a tremendous burden on them and silenced their struggle to define what they hoped for, which at times was relief through death" (Kristiansen *et al.,* 2014).

Participants expressed the need for respect for their faith, asserting their right to perform rituals of religious significance at the end of life. One participant, reflecting on the ideal death, emphasized the significance of religious rituals and being surrounded by trusted individuals: *"I would prefer to have my children with me, and if that's not possible, then I at least want to be with someone that I can trust if I am conscious. If I am not conscious, I don't know. But I will be pleased to have someone stay with me and pray to God when I die.*" (Venkatasalu *et al.,* 2014).

Religious learning for children and attendance at religious activities were emphasized as integral aspects of emotional support for children with parents who were facing terminal illness, reflecting the significance of religious teachings in present and future emotional resilience. *"The other thing that worries me is that she is 13, she does not know namaz [daily prayer] yet, she is still reading the Qur'an. I was saying to her we really need to get on top of that because that is a big obligation as a parent…I say to her that that is really important because I feel that, you know, sometimes you will get comfort from that as well."* (Gaveras *et al.*, 2014).

While faith and cultural practices hold immense importance for many, challenges persist in integrating these beliefs within existing healthcare systems. Tensions arose between healthcare professionals' understanding of care and patients' expectations rooted in cultural and religious beliefs. Participants highlighted inadequacies in care packages, particularly concerning personal care and issues around nudity, illustrating the discord between institutional care and personal beliefs which can emerge: "*In my religion [Islam] administering simple hygiene at the time of death should be left to the family and [my religious] community rather than non-Muslim doctors or nurses.*" This was rooted in a belief that care provided by an individual of a different gender than the patient could have adverse spiritual consequences (Samanta *et al.,* 2018). One individual reflected on the significance of the burial process as a means of finding solace, noting how processes in the dominant culture might clash with their preferred rituals: *"When somebody's buried, it kind of eases the pain when they've gone. But if they're hanging around in the mortuary or you know, in a freezer somewhere, you've always got that kind of like pain that they're still, they haven't gone yet"* (Hossain *et al.,* 2022).

In Samanta *et al's* (2018) study, some participants were wary of medical treatments which aimed to preserve life in an impaired state of consciousness: *"Look at the Liverpool Care Pathway. The main option is one of pain relief and you are dosed up. I do not believe in that. We, as Muslims, want to be alert for as long as possible in order to read our final prayers (Shahada) which is a declaration of faith*". Another Hindu participant noted that "*If you are dying you need to read Bhagavad Gita. You pass from one body to another. The person should be conscious for that*."

Some participants reported more positive experiences where staff were supportive of their religious practices: “*I used to go to the temple every day so the nurse would phone me and say I’m making my way to you now. I’ll clean him now and you go to the temple so that was really nice*.” (Owens & Randhawa, 2004). Another participant whose main doctor was a white British male reflected that “*we were allowed to do everything according to our religion*”. The use of the word "allowed" in the participant's statement could imply a perception of needing permission or approval to practice their religious beliefs within the healthcare setting, as well as suggesting a sense of accommodation or acceptance from their doctor.

Gaveras *et al.,* (2014) also heard accounts from some participants who withdrew from their religious communities due to perceived stigmatization. Although religious beliefs have been noted as a significant coping strategy for South Asian Muslims dealing with life-threatening illnesses, it was observed that religious leaders such as imams were not consistently identified as a primary source of social support in this study which looked at experiences of parents of young children.

Participant’s accounts highlighted the complex interplay between faith, cultural practices, and challenges faced by South Asian Sikhs and Muslims in navigating end-of-life discussions. Their narratives underscore the need for greater integration of cultural and religious beliefs within healthcare settings, as well as the need to refrain from making assumptions that all members of one group will share the same preferences.

2.2 Gendered Perspectives on end-of-life dynamics

The dynamics of end-of-life care among South Asian communities in the United Kingdom involved some gender disparities and cultural intricacies which shaped the responses of both carers and patients. Women consistently voiced their societal duty to care for others and to persevere in their familial roles: *"In Asian families, the women are expected to just get on with it, carry on with it no matter what"*, "*It is very cultural for women, you know, to not moan about anything*" (Clarke *et al.,* 2023). These portrayals highlight the pressures exerted on women to shoulder familial responsibilities perhaps regardless of any personal distress. Conversely, men grappled with the erosion of their provider role due to illness, leading to difficult feelings of inadequacy. "*I feel stuck. […] I would like to do some work […] It helps to get out of the house. Household expenses are really quite high you know that you can't really manage without working*," echoed the distress of being unable to contribute financially (Kristiansen *et al.,* 2014).

Cultural norms dictating gender roles also influenced how pain and emotional distress were communicated and addressed. Men often refrained from disclosing emotional struggles: "*Being a man, kind of being strong, he just feels that he can't open up*" (Clarke *et al.,* 2023). This reticence in discussing pain may hinder men's access to timely medical care and familial support, exacerbating their suffering. Kristiansen *et al.* (2014) also encapsulated the nature of these dynamics in their article, noting that "motherhood featured in most female participants' accounts, whereas the ability to provide for one's family was central to the accounts of most of the males".

In Gaveras *et al's* (2014) study, healthcare providers frequently referred to the gender of the caregiver, with some assuming that female family members played a predominant role in offering social support to both the patient and the children within the family: "*It has been my experience with the few other Muslim women I have dealt with as well – they have come on their own without their husbands or their partners have seemed to be very much in the background. Muslim women seem to have a more distant relationship with their husbands…White couples do seem to come as equals – may well be that they are estranged equals – but they are there as equals, it seems that South Asian women are much more submissive*." These accounts had the potential to overlook the potential contributions men could make in the caregiving process. The trend of South Asian women undertaking caregiving responsibilities at the end of life mirrors a prevailing societal norm in the United Kingdom, where there is a disproportionate responsibility placed on women as primary caregivers (Age UK, 2019, Washington, *et al.,* 2015).

Theme Three: Family roles and expectations regarding palliative care

3.1 Family as caregivers

The intersection of cultural expectations, familial responsibilities, and personal struggles shape the experiences of South Asian Sikhs and Muslims confronting life-limiting illnesses in the United Kingdom. As noted by Cowan (2014), respect for one's elders is a core belief for many in Sikh populations, meaning that carers appeared to have strong respect for their elders as well as a desire to fulfil their wishes around care. It appeared that carers saw their roles as primary caretakers and guardians, rather than medical professionals: "*My mother-in-law did not want to be looked after anywhere else. I was* *very close to her so I did not feel that I was doing any [extra] work. I explained that I would look after her as much as I can. I wanted what my mother-in-law wanted*…" (Cowan, 2014). Many carers expressed a deep willingness and responsibility to care. There was a reluctance to opt for care homes or hospices, reflecting a desire to preserve dignity and familial pride: *"Our personal thing is that he deserved to be looked after with respect. We can talk about him in a way with pride"* (Cowan, 2014).

For one patient, absolute faith was placed in her children to make key decisions around her death, without feeling a need to discuss her options with them: "*My children will carry out everything for me… It is trust*" (Venkatasalu *et al*., 2013). Carers took on key roles in communicating with healthcare staff and advocating for their loved ones (Kristiansen *et al*., 2014). A carer in one study described leaving her job to take on her husband's care alongside the care of her child: *"I did it myself, I still do now…Enough, what else can I do, he needs care. I used to go out to work and I had to leave that about 6 months ago. It was difficult having a young child too*" (Gaveras *et al*., 2014).

Some carers tried to seek support from family members living abroad, but unfortunately their visas were sometimes denied despite having letters in support from medical staff (Gaveras *et al*., 2014). Some participants reported stigma associated with seeking help from others outside of the family: "*Because culturally we have to look after our parents. We'll just deal with. We don't want extra support, whatever it is, you see… I think that's sort of negative. By asking somebody else, it could sort of like a negative on them"* (Hossain *et al.,* 2022).

Owens & Randhawa (2004) found that staff tended to have strong perceptions that South Asian families would look after each other and have large family networks: "*I think it's a very big culture thing, you know, the Asian families have a lot of family around them for a support network*". The authors note that this may be an out-of-date stereotype. These assumptions may also reduce staff member's ability to identify when a carer may be struggling: "*Obviously at first, it was rewarding but then it became very difficult just watching ... dealing with it ... watching him*" (Cowan, 2014). Feelings of inadequacy and a lack of external support were prevalent among carers: "*I was not able to cope and I admit that. If someone else was there with me I would have been fine. I was on my own*." (Cowan, 2014). Cultural values influenced the caregiving approach, with many carers showing a reluctance to seek external help. The dedication of family members to remain by the side of their dying relatives showcased a clear sense of duty and an avoidance of potential guilt (Venkatasalu, 2017).

3.2 Roles and expectations of the new generation in end-of-life care

Many participants expressed a strong connection to their cultural roots and expressed concerns about the potential loss of their heritage across subsequent generations living in the United Kingdom. For others, social networks that existed prior to their emigration no longer existed and their new understanding of home reflected this (Venkatasalu *et al*., 2014). One patient spoke about how in the past it was more common for children to take their parents' ashes to their home country, while now "*most of the children start putting the ashes in the river here*" (Hossain *et al.,* 2022). Some participants expressed a concern that the core tenets of their culture could be lost unless they set a strong example for their children. Despite this, participants spoke of their children adopting a different approach: "*If we don't follow our culture, our son or daughters will not do the same for us. They won't care for you when you are dying. But some people will die here and send their ashes to India. [But] my daughter said to me, look mum. If you die, I am going to spread your ashes here. I don't want to fly to India for that*" (Venkatasalu *et al*., 2014). Some professionals also felt that receptiveness to services varied with age, with younger people being more likely to explore and identify what was on offer (Randhawa & Owens, 2004).

Owens & Randhawa (2004) paid heed to the dangers of stereotyping when it comes to South Asian families, explaining that "there was a ready acknowledgement that South Asian families may not have the desire or ability to 'look after their own', especially within a context of rapid social and demographic change". While care at home appeared to be readily adopted by the interviewees, some expressed doubt that successive generations could continue to adhere to this ethos: *"I was brought up very nicely—this [caring for mother] is payback; nothing is free. I told my mother you are very lucky [because] our children they are not the same they will send us off to a home.*" (Cowan, 2014). Another participant reflected on how in the past sending a relative to a care home or hospice might have led to stigma from others but felt that now things were changing: "*So people would have talked, very much, very much so. It's not something you do [sending relatives to a care home] but it's getting more and more common*" (Cowan, 2014).

Theme Four: Navigating Challenges Across Care Settings and Healthcare Interactions

4.1 Lack of awareness of services

Throughout the studies examined, there existed a notable lack of awareness about available services amongst many participants, with health professionals also noting this trend, particularly amongst older adults. In Cowan's (2004) research, the author explained that a lack of awareness of specialist palliative care services was voiced strongly by most participants, and may have accounted for periods of time where carers and patients were left unsupported. Many participants did not know that palliative care services could be provided in one's own home: "*So your hospice, you actually go into people's homes. We don't even know about that, we don't even know about hospice at home service*!'" (Cowan, 2004).

Moss *et al.,* (2023) suggested in their study that South Asian communities had only a "vague awareness" of palliative care services. This was despite efforts made to bolster awareness within these communities, such as relocating a hospice from Bradford's outskirts to a more ethnically diverse inner city and employing a South Asian liaison worker. A prevailing lack of awareness persisted among many individuals regarding the existence of professional end-of-life support, unless they had been directly involved in providing care to a relative.

Randhawa & Owen (2004) found that nearly all participants were only aware of individuals being diagnosed with cancer at terminal stages. This suggests that providing information and raising awareness could not only lead to a better understanding of the disease but also demonstrate that curative treatment is often possible. No one in the focus group in this study had heard about palliative care services. One staff member noted: "*There don't* *seem to be many (South Asian Patients) attending there and I've just spoken to one and she's got no idea what it's about that's why she wouldn't go. But when we actually got her to go, she started attending and she really likes it*…", highlighting how some patients may be missing out on services which could positively impact them or their families.

Moss *et al.,* (2023) found that healthcare professionals had minimal involvement in developing advance care plans, often emphasizing a narrow medical perspective, and failing to integrate voluntary and community services as well as cultural considerations around what makes a "good" advanced care plan. Amongst participants in Randhawa *et al's* (2003) research, advice was sought about services from family and friends, as well as posters and leaflets. Most patients and their families had a restricted understanding of their own or their relative's health condition and were only partially aware of the available services available to them. Similarly, Venkatasalu *et al*. (2014) found that there was little discussion about hospice care among the participants, potentially due to a lack of awareness or familiarity with such services. Most participants only discussed hospital care as the alternative to receiving care at home.

Despite efforts to tackle ethnic disparities within the South Asian community, many inequities persisted. There was a lack of comprehensive understanding and implementation of initiatives aimed at addressing the diverse needs and preferences of individuals from various cultural and faith backgrounds in end-of-life care planning (*Moss et al., 2023*). Professionals agreed that information about end-of-life care should be provided at an earlier stage in the illness trajectory. There was acknowledgment of the need for building trust within these communities to effectively understand and cater to their specific requirements (*Moss et al., 2023*).

4.2 Experiences with hospital and homecare services at end of life

A prominent thread running through the participants' narratives was the significance of cultural considerations in end-of-life care in both medical and home-based settings. This was particularly evident in the difficulties faced when homecare staff did not adhere to cultural norms. The home was seen for many as a locus of cultural identity and intimacy, and most participants expressed a preference to die at home. Despite this, challenges arose in achieving patients' wishes due to crises and the family's perceived inability to handle the patient's end-of-life care. Practical constraints emerged regarding home-based care, especially for individuals without extended family support and limited space. Some participants believed hospitals might offer better care due to the emotional and practical difficulties involved in managing a dying person at home (Venkatasalu *et al,* 2014). One carer recounted a situation where a homecare worker declined to remove their shoes indoors, which was culturally important, leading to a conflict: "*I asked her to take her shoes off...she went back and complained*" (Wilkinson *et al.,* 2014). Carers highlighted their struggle in securing culturally appropriate care, often encountering limited availability of staff who could cater to their cultural needs: "*When the carer requested another homecare attendant, he was told there were a limited number of attendants available*" (Wilkinson *et al.,* 2014).

Some carers and patients had negative experiences of hospital care, which lead to guilt and frustration on the carer's part: "*He suffered a lot because of their lack of attention. Next morning, when I went early, I felt very bad. I saw one cup of cold coffee and his capsules ... everything is there … (in front of him), but nobody bothered about how the man can take of himself*." (Venkatasalu, 2017). Another participant explained that their loved one was left in an unhygienic state, leaving them reluctant to put their faith in healthcare staff: "*So, how can we trust such people for our problems?"* (Venkatasalu, 2017).

One individual recounted their friend's husband receiving excellent care at the hospital, expressing satisfaction with the attentive treatment provided by nurses which encompassed culturally appropriate language, kindness and appropriate medical care: *"He was taken care by nurses very well. Everyone liked him and they called him uncle ... so we also have that kind of experience. They gave him his food, medication and talked nicely with him"* (Venkatasalu, 2017).

Conversely, inadequate communication led to frustration and delayed access to essential treatment. A participant shared their exasperation: "*We were getting fed up with the GP...they would say 'well I just saw you last week, I can't do anything, it's just pain'*" (Clarke *et al.,* 2023). Furthermore, misunderstandings and disbelief regarding reported symptoms resulted in misdiagnoses and postponed necessary care in some cases. This was evident when a participant expressed dissatisfaction at a doctor's analysis of their symptoms: "*I told him...I don't think it's sciatica...why am I losing weight, why am I not eating*?" (Clarke *et al.,* 2023).

Participants faced multifaceted challenges when accessing and utilizing formal support services. Negative experiences with these services included perceptions of long delays, inadequate care packages, and language barriers (Hossain *et al.,* 2022). Cultural and religious obligations sometimes clashed with scheduled support services, leading to restricted access or non-participation. Conflicts between children's religious activities and scheduled therapy sessions hindered one participant's involvement in emotional support services, impacting the ability of the family to access these resources (Gaveras *et al.,* 2014).

In certain instances, healthcare providers encountered challenges when determining the involvement of family members in caring for the patient. For example, one healthcare provider observed that a patient's young daughter played a significant caregiving role, aligning with family's preference to be the main providers of support: "*I think (daughter) had helped her mum so much in the earlier stages – helping her managing her menstruation, showering, and everything was so…it's such a lot*". However, interviews with the patient showed that she did not think her daughter should take on such responsibilities: *"My daughter was only 12 and I was told you've got family. I said for God's sake, my daughter is only 12. What you want me to do tell her to drop out of school and stay with me all the time?"* (Gaveras *et al.,* 2014).

Finally, individuals in one study sought alternative or complementary therapies for pain relief, such as CBD oil or herbal remedies, with some perceiving prescribed medications as 'unnatural' (Clarke *et al.,* 2023). Some participants from Pakistan expressed a tendency to endure pain and to use home remedies before seeking hospital care, showing a cultural inclination toward self-reliance and traditional methods of treatment (Clarke *et al.,* 2023).

Discussion

The aim of this review was to explore the experiences and needs of South Asian patients and their carers regarding end-of-life and palliative care services in the United Kingdom, while also incorporating the perspectives of healthcare staff working in these services. The themes identified were: barriers and facilitators to discussing and preparing for end of life; the impact of identity and culture on end-of-life practices and rituals; family roles and expectations regarding palliative care, and navigating challenges across care settings and healthcare interactions. The review highlighted the importance of cultural competency and effective communication in providing palliative care within South Asian communities.

According to the NHS's 2023 framework for specialist palliative and end of life care services, effective end-of-life care involves treating individuals with dignity and respect, emphasizing a person-centred approach. This includes ensuring equitable access to services, maximizing comfort and well-being and coordinating care through local systems which are supported by well-prepared staff (NHS England, 2023). However, the findings in this review indicate that the experiences and perspectives of South Asian patients and families often did not align with these ideals, suggesting a need for more culturally sensitive and individualized approaches to end-of-life care.

The barriers to accessing palliative care services among South Asian populations, as identified across these studies, included stigma around discussions of death, attitudes towards palliative care and caregiving, ineffective integration of cultural and religious practices into medical care, language barriers, a lack of knowledge about available services, and disappointment with healthcare services provided. The findings emphasize the significance of a public health approach in palliative care service development, advocating, as other studies have recommended, for fostering community inclusion and access to information (Moss *et al.,* 2023).

Theme one showed a reluctance to discuss end of life among many participants from South Asian backgrounds. *Moss et al., 2023* make an important point that their findings suggesting a general lack of awareness of palliative care services align with national and international evidence illustrating that the general public demonstrates limited knowledge of such services. They further note that this limited awareness may also reflect a broader societal avoidance to confront the topic of death. For example, terror management theory, as outlined by Greenberg & Arndt (2012), suggests that to cope with the potential distress caused by the recognition of our mortality, individuals construct cultural worldviews that provide a sense of order. These cultural worldviews, which can include religious beliefs, and other belief systems, can offer a sense of significance transcending our physical existence. By pushing away or suppressing conscious contemplation of death, individuals can maintain their cultural worldviews and self-esteem. This resonates with theme one in this review, which highlighted the avoidance around discussing death among some South Asian participants.

Theme one further revealed that many healthcare staff felt ill-equipped to navigate complex end-of-life discussions, expressing discomfort due to fears of causing distress.

It was possible that at times inaccurate assumptions were made about family caregiving dynamics. Providing healthcare professionals with not only cultural competency training but also with adequate emotional support and practical guidance could better prepare them to sensitively broach difficult situations and conversations. Fang *et al.* (2016) in their scoping review of palliative care services in Canada, found that interventions aimed at improving cultural humility mainly centred on education for healthcare providers. Similarly in this review, the absence of practice-oriented interventions created a void in understanding effective practices in various care settings like homes, hospitals, and hospices. Guidelines on spiritual and cultural aspects of end-of-life care could facilitate a more person-centred approach. Care agencies and staff members in hospital settings should be aware of and consider cultural beliefs regarding caregiving by individuals of the opposite sex.

Theme one further highlighted how patients with limited English proficiency faced significant communication challenges, sometimes having to rely on family members or non-verbal cues to convey needs. Language barriers created communication challenges, with sometimes contrasting views between staff and patients on using family members as interpreters. Patients often preferred family for cultural reasons, while some providers had concerns around accuracy, privacy, and the emotional toll on children asked to translate. This replicates findings in other studies highlighting the often-profound impact of language barriers on care (Healthwatch, 2022).

An initial attempt to assess and unify scientific understandings of death emerged in 1972 (Kastenbaum & Aisenberg). This work proposed that every culture possesses a framework that serves various purposes, such as forecasting death, endeavours to avoid death, attitudes toward the dying, handling of deceased bodies, and societal traditions post-death. The findings from Theme 2 in the present review align with and provide illustrations of how such cultural frameworks shape attitudes and practices around death and dying within South Asian communities. For example, this theme highlighted the profound role of faith in sustaining hope amidst terminal illness for some, while also revealing tensions between religious practices around death and existing healthcare systems focused on life preservation.

Theme two highlighted challenges which arose when integrating cultural beliefs around issues like modesty with standard healthcare practices. Gender norms influenced caregiving roles, with some women expected to persevere through difficulties, while ill men struggled with an inability to provide financially. Cultural tendencies often meant that men tended to avoid discussing emotional difficulties.

Theme three provided insights into the role of family caregivers and evolving expectations across generations regarding end-of-life care within South Asian communities. This included a strong sense of duty and responsibility to care for loved ones at home, as well as challenges in maintaining cultural traditions and practices amidst changing social dynamics. Some participants sensed that traditional cultural and gender-based expectations for care, as well as burial practices, might be evolving with the emergence of a new generation. The potential for changing dynamics regarding care has also been noted in other studies. For instance, Hossain *et al.* (2019) observed that while older Bangladeshi males traditionally relied on female family members for support and care, such care has become less accessible as more women enter the workforce, with some women feeling conflicted about their roles.

Finally, theme four showed a lack of awareness about available care services, particularly among older adults in South Asian communities. For those who did engage in services, cultural considerations were significant, with challenges arising when homecare and hospital staff did not adhere to cultural norms. Similar findings have been reported in studies examining access to various health services for South Asian groups, for instance, in the context of mental health, where a recent systematic review has argued that that institutional racism and cultural insensitivity contribute to the marginalization of South Asian service users, hindering their access to quality mental healthcare services (Prajapati & Liebling, 2022).

Theoretical and clinical implications

This review underscores the urgent need to enhance cultural competency in palliative care delivery for South Asian communities. With this population comprising the United Kingdom's largest ethnic minority group, culturally tailored end-of-life services are crucial (Office for National Statistics, 2022). Integrating the findings of this review into clinical practice could help to enhance the quality of care and support for South Asian individuals facing end-of-life.

Clarke *et al.,* (2023) in their study on pain management in cases of serious illness, recommend co-producing understandable written information in the context of pain medications, paying closer attention to cultural requirements, and increasing access to medical interpreters, suggestions which were all corroborated in this review and could be applied in the context of palliative care. NICE in their 2004 report on cancer services also recommended that there should be active patient and caregiver involvement in cancer and palliative care services as well as the establishment of supportive systems, including self-help activities and peer support in community settings. Across the studies in this review, caregivers and patients did not seem to have experiences or opportunities to provide their input. Addressing this gap by actively involving patients and caregivers in the development and evaluation of palliative care services could improve the relevance and effectiveness of these services for South Asian communities.

Improving language services, addressing systemic barriers such as mistrust of services, and fostering cultural humility among healthcare professionals are essential components in delivering equitable services. Strategies involving bilingual workers and community engagement were helpful in some cases to bridge language and cultural gaps. However, providing information about available services without addressing structural barriers and broader gaps within health systems could serve to perpetuate the exclusion of some minoritized groups from accessing palliative care services (Moss *et al.,* 2023).

The review suggested a clear role for improved education, support and guidance for staff members working across these settings, including awareness of potential gender norms which can influence caregiving responsibilities and communication of pain and emotions, not overlooking the potential for men to be involved in caregiving, recognizing when family caregivers, who are often women, may need more support and avoiding assumptions of self-sufficiency, providing information on services earlier in the illness trajectory, and involving community services in addition to medical perspectives on advance care planning.

Of significance in this review was the absence of psychology-related discussions within the reviewed papers. Notably, only two participants across these studies mentioned receiving or being offered any psychology support. The British Psychological Society (“BPS”, 2008) underscores the pivotal role of psychologists in these settings; however, psychology did not emerge as a primary support source for patients, families or staff members in this review. It remains unclear whether this absence of discussion on psychology services was due to a lack of focus on the role of psychology in the studies, or the underreporting of such services by participants. The absence of discussion on psychology services might arise from a broader scarcity of psychology resources or a failure to adequately engage with people from minority ethnic groups in these contexts.

Psychologists can take a key role in supporting not only patients in these settings, but also in providing emotional support and training based on psychological theory and principles to healthcare professionals. In various studies examined in this review, healthcare providers expressed concerns about inadequate training and confidence in discussing end-of-life matters with patients, suggesting a more prominent role for psychologists to offer support in this area.

Research pertaining to the views and experiences of clinical staff working in palliative care has predominantly been conducted with nurses, with relatively few studies sampling clinical psychologists (Cramond *et al.,* 2020). A study involving psychologists working in palliative care services highlighted the importance of understanding the perspectives of clinical psychologists, given their crucial role in supporting other healthcare professionals in these settings (Cramond *et al.,* 2020). It was noted that further exploration into the roles, challenges, and viewpoints of clinical psychologists in palliative care services could offer valuable insights into how psychology services are integrated and accessed, particularly concerning minority groups. Future research should also continue to represent the views of minority groups across various domains including end-of-life care, as well as exploring how factors like race, ethnicity, sex, sexuality, socioeconomic status, and cultural background shape unique experiences of end-of-life care. Studies could additionally look to the experiences of specific south Asian communities rather than collapsing sub-groups into a single category.

According to the Care Quality Commission's 2016 report, over 90% of hospices were rated as good or outstanding at that time. In contrast, 42% of end-of-life care services in acute hospitals were deemed inadequate or in need of improvement. Within the broader theme of a lack of awareness of available services, a significant lack of awareness about hospices was evident among many participants from South Asian backgrounds. Raising awareness about hospices amongst these groups is essential to ensure that individuals and their families can make informed choices about the support on offer.

In terms of improving service provision for people from minority ethnic groups, some providers suggested that increasing the frequency of appointments might compensate for communication barriers that exist (Wilkinson, Randhawa *et al.,* 2017). Lastly, the findings point to other areas for improvement, such as recommendations by NICE (2004) suggesting that multidisciplinary teams should have access to appropriately qualified spiritual caregivers who can serve as a resource for patients, carers, and staff. This provision seemed to be absent across the studies or at least not mentioned, indicating a potential area for improvement in providing comprehensive palliative care.

Strengths and limitations

To the best of the author’s knowledge, this is the first systematic review to explore psychosocial aspects of palliative care services for South Asian people living in the United Kingdom. The study incorporates perspectives not only from South Asian patients and caregivers but also from staff members working with this population, and all studies were of medium or high quality. The review provides a holistic view of the challenges and dynamics within palliative care settings. Improving the research base and discerning nuanced differences within ethnic minority groups' healthcare experiences can help in dismantling inequalities affecting these groups. This work may also have implications beyond the United Kingdom, since South Asian communities constitute large minorities in other western white majority countries such as Canada (Statistics Canada, 2022) and

Australia (Australian Bureau of Statistics, 2022) and also suffer from inequities in palliative care provision (Dosani *et al.,* 2020; Shanmugasundaram & O'Connor, 2009).

The study's focus solely on qualitative research might limit the findings. Incorporating quantitative studies could provide a more multifaceted view by quantifying the relative impact of specific barriers on hindering access to palliative care services among South Asian populations. As the reviewed studies primarily originate from medical-focused journals, there might be an underrepresentation of psychological or interdisciplinary viewpoints in understanding the psychosocial aspects of palliative care for South Asian individuals. While themes common to all South Asian groups have been identified, it is important to recognize that significant differences exist within these groups. Collapsing South Asian groups into a single category can overlook the substantial diversity among them.

Conclusion

By synthesizing qualitative research, this study presented crucial insights into the experiences and perceptions of South Asian patients, caregivers, and staff members within palliative care settings. The identified themes highlighted the multifaceted challenges faced by this population, encompassing barriers to discussions about end-of-life, the impact of identity and culture on care practices, family roles and expectations, and the complexities in navigating healthcare interactions.

The findings underscore the need for culturally sensitive and inclusive palliative care services. Barriers hindering access to palliative care for ethnic minorities, including linguistic challenges, lack of awareness, cultural insensitivity, and systemic inequalities, necessitate targeted interventions. Strategies involving community engagement, improved language services, and fostering cultural humility among healthcare professionals are necessary components in delivering equitable and dignified end-of-life care for South Asian individuals. Moreover, this review highlights the paucity of discussions on psychology services within palliative care for minority groups, urging further exploration into the roles and challenges faced by clinical psychologists in providing inclusive and supportive care.

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Part 2: Empirical Paper

Understanding Barriers and Facilitators to Dementia Risk Reduction behaviours among Indian Populations in the United Kingdom: A Thematic Analysis

Abstract

Aims: The aim of this study was to better understand the attitudes of cognitively healthy adults from Indian communities in the United Kingdom towards lifestyle recommendations for dementia risk-reduction.

Method: Through semi-structured interviews and thematic analysis, this qualitative study examined dementia perspectives and risk-reducing lifestyle changes among fifteen UK-based participants of Indian ethnicity. Participants consisted of first-generation immigrants as well as subsequent generations maintaining ties to their cultural identities and communities.

Results: Three main themes and seven sub-themes were identified from the analysis; the main themes were: 1. Navigating the Complexities of Dementia Awareness and Discourse in South Asian Communities 2. Determinants of Healthy Lifestyle Engagement: Personal and Contextual Factors and 3. Diverse Perspectives on Health: Accessing Medical Relationships and Other Information Sources.

Conclusions: The findings underscore the need for culturally tailored approaches to promote dementia awareness and preventative lifestyle changes among ethnic minority communities. Efforts should address stigma, language barriers, and beliefs normalizing cognitive decline as a natural result of aging.

Introduction

Dementia is typically defined as a clinical syndrome of cognitive decline severe enough to interfere with social or occupational functioning (Chertkow *et al.,* 2013). The prevalence of dementia is rising, with projections indicating a 57% increase in the number of people living with dementia in England and Wales by 2040 (Ahmadi-Abhari *et al.,* 2017). According to the 2021 census, South Asian people constitute one of the largest ethnic minorities in the United Kingdom (Office for National Statistics, 2022). In 2013, estimates suggested that over 25,000 people from ethnic minority groups were living with dementia in the United Kingdom (All-Party Parliamentary Group on Dementia, 2013). This number is expected to double by 2026, with the largest increases projected among South Asian communities (Alzheimer's Society, 2022), representing a sevenfold increase over forty years, compared to just over a twofold increase in the numbers of people with dementia across the whole U.K. population (Public Health England, 2021).

These groups are more prone to risk factors such as cardiovascular disease, hypertension, and diabetes, which increase dementia risk (Public Health England, 2021). The rising prevalence of dementia therefore presents a major public health challenge, necessitating a strong focus on prevention and risk reduction strategies. As there are currently no pharmaceutical treatments for dementia, efforts have concentrated on addressing modifiable risk factors.

The Lancet Commission on dementia (Livingston *et al.*, 2020) identified twelve modifiable risk factors for dementia, including less education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, low social contact, excessive alcohol consumption, traumatic brain injury, and air pollution. If these risk factors were eliminated from the population, there would be a 40% decrease in the incidence of dementia (Livingston *et al.*, 2020). Many of these risk factors cluster around general inequalities, which occur at higher rates in minority ethnic populations (Livingston *et al.*, 2020). For example, risk factors such as type two diabetes are higher in South Asians than in other populations (Gupta, Singh, & Verma, 2006). In addition to being more vulnerable to some of these risk factors, ethnic minority populations are found to be under-represented in health services for dementia and may delay seeking help (Purandare, Swarbrick, & Burns, 2007; Giebel *et al.,* 2019).

A recent large-scale cohort analysis explored the population attributable fraction of these twelve modifiable risk factors for dementia (Bothongo *et al.,* 2023). By stratifying the risk factors by ethnicity, the study aimed to better understand which risk factors contribute most significantly to dementia in different groups, thereby allowing for more targeted prevention efforts. The results indicated that even in a relatively wealthy and healthy population, there were significant ethnic disparities in the impact of modifiable risk factors on dementia. For example, interventions for midlife hypertension are of greater priority in South Asians and Black populations, while depression and alcohol consumption were significant concerns among South Asians (Bothongo *et al.,* 2023).

In terms of knowledge about dementia amongst various populations, a 2018 national survey in the United Kingdom, involving over 2,000 adults, revealed that only 34%

believed lifestyle changes could reduce the risk of dementia, while 22% thought dementia was an unavoidable consequence of aging. A significant majority, approximately 75% of respondents, expressed an interest in obtaining additional information from healthcare professionals regarding personal risk factors associated with dementia. This underscores a need for targeted public education, tailored to diverse communities (Alzheimer's Research U.K., 2018).

Another study compared dementia knowledge between Indian and white UK/Irish/European participants, finding that both groups had a limited understanding of the causes and symptoms of dementia (Purandare *et al.*, 2007). However, older Indian people demonstrated significantly less "basic knowledge" compared to their counterparts. In this context, "basic knowledge" encompasses an understanding of the prevalence, causes, and symptoms of dementia, as assessed by the Dementia Knowledge Questionnaire (Purandare *et al.*, 2007). These findings suggest that public education efforts should focus on increasing awareness of dementia risk factors, with additional attention to bridging knowledge gaps among different demographic groups.

Many factors influence an individual's capability or inclination to adhere to lifestyle advice. These factors include individual factors, healthcare providers' ability to tailor their practice to individual patients' needs, as well as the organizational and environmental contexts in which these elements converge (Lutfey, 2003). In one systematic review exploring adopting of healthy lifestyle choices in mid-life populations, the authors identified several barriers to adopting healthier lifestyle choices, including a lack of time, access limitations, financial constraints, ingrained attitudes and behaviours, low socioeconomic status, and knowledge gaps. Conversely, facilitators included well-being associated with physical activity, health benefits like healthy aging, social support, clear messaging, accessible websites, and previous experiences with illness (Kelly *et al.,* 2016).

Identifying, diagnosing, and treating dementia within United Kingdom ethnic minority communities can pose significant challenges. These difficulties stem from low literacy rates, language barriers, and the absence of screening and diagnostic tools tailored to this cultural group, hindering effective care provision (Kenning *et al.,* 2017). A lack of awareness and misconceptions about dementia also persist. Many South Asians view memory impairment as an inevitable consequence of normal aging or attribute dementia symptoms to religious beliefs. Such differing conceptualizations and explanatory models for the manifestations of dementia may lead to diminished help-seeking behaviours among those affected and their caregivers (Kenning *et al.,* 2017).

There may also be different ways of understanding and reacting to dementia amongst ethnic minority communities (Lawrence *et al.,* 2011; Roche *et al.*, 2021). One qualitative review found that amongst ethnic minority groups, participants reported that dementia was not likely to affect them, that services were often inappropriate or disrespectful, and that families frequently cared for their own loved ones when formal services were not perceived as meeting their needs. For many individuals, their understanding of dementia was intertwined with their spiritual beliefs and religion (Roche *et al.*, 2021).

Currently, there are few studies specifically aimed at understanding the uptake of health-promoting behaviours for dementia prevention among South Asian groups in the United Kingdom. While Bosco *et al.* (2020) conducted a content analysis exploring attitudes towards lifestyle changes for dementia risk reduction, their study primarily involved a majority white sample. Cations *et al.* (2018) performed a systematic review of public attitudes towards dementia prevention and treatment across multiple countries, but this review did not focus specifically on South Asian groups. Additionally, a meta-synthesis by Poole *et al.* (2021) examined knowledge of dementia among South Asian participants in the United Kingdom and other countries; however, it did not specifically address attitudes towards preventative lifestyle measures.

The BME (Black and Minority Ethnic) classification, often used for research and policy purposes, encompasses a wide range of populations including South Asians from Pakistan, India, Sri Lanka, and Bangladesh, as well as other minority ethnic groups. While such categorization devices can shed light on potential commonalities, they can also overly simplify the inherent heterogeneity within these populations, meaning that research should aim to provide more nuanced information pertaining to participant's specific contexts and identities (Roche *et al.,* 2021). Better understanding of ethnic minority attitudes towards dementia and dementia prevention may allow us to shape and offer appropriate health advice and treatment options.

The aim of this study, therefore, was to better understand the attitudes of cognitively healthy adults in Indian communities in the United Kingdom towards lifestyle recommendations for dementia risk-reduction. Investigating attitudes among these communities could yield valuable insights to develop dementia prevention approaches and educational resources that are tailored and culturally resonant for these populations.

Methods

Ethics

This study was approved by the Ethics Chair for the Clinical Psychology Research Department at UCL, under Project ID number 24783/001 (Appendix 3).

Recruitment

To ensure inclusivity and accessibility, participants were recruited through community and religious organizations in areas with a high density of ethnic minority residents, as well as via social media (Facebook groups) and local posters. Participants were given the choice to conduct interviews in English or use an interpreter to communicate in their native language.

Inclusion criteria

Cognitively healthy adults aged forty and above from South Asian populations including Afghanistan, Bhutan, Bangladesh, India, Maldives, Nepal, Pakistan and Sri Lanka were invited to take part in this study (Britannica, 2024). Eligible participants needed to be either first-generation or subsequent-generation immigrants to the United Kingdom who maintained a cultural identity and/or links with their South Asian community. The age criteria were selected as it represents a mid-life period when risk factors for dementia become more prevalent, allowing the research to explore attitudes towards modifying these risk factors during an optimal intervention window (Public Health England, 2021).

Exclusion criteria

Exclusion criteria included individuals who were not cognitively healthy, those younger than 40 years old, and individuals from non-South Asian backgrounds. Participants who did not maintain cultural identity or links with their community, or who could not communicate effectively in English or through an interpreter, were also excluded from the study.

Guidelines from prior research indicate that studies employing thematic analysis and semi-structured interviews largely reach data saturation after conducting twelve interviews, which informed the target sample size for this study's recruitment process (Guest *et al.,* 2006). After being approached, interested participants were given a copy of the information sheet (Appendix 4) with the study’s consent form (Appendix 5), and were given at least 24 hours to read through it and share any questions or concerns. Prior to participating in the study, participants provided written consent via email, and at the start of each interview session, they gave oral consent, which was recorded. Participants were given the option of having their interviews take place in person in a community setting, online, or by telephone.

Data Collection and Management

Fifteen semi-structured interviews were conducted by video call (N=4, all through Microsoft Teams) or telephone (N=11), in accordance with each participant's preferred option. Interviews ranged from 25-60 minutes, with an average interview time of forty minutes, and were recorded using an encrypted digital audio recorder. All participants took part in one semi-structured, audio-recorded interview and completed a demographic survey (Appendix 6). The data on health and lifestyle factors collected were based on the Lancet Commission on Dementia (Livingston *et al.,* 2020) and are known modifiable risk factors for dementia.

Audio files of interviews were transcribed verbatim using software approved by the university (Microsoft Transcribe), while data for analysis was managed using NVivo. Thematic analysis was used to analyse the data, focusing on attitudes towards dementia and dementia-prevention lifestyle changes. Following informed consent, research identification numbers were used to refer to participants for the purposes of preserving anonymity. Transcriptions of audio recordings were also anonymized. Consent was obtained through email and through either a phone call or a video call via Microsoft Teams. Participants were informed clearly through the consent and information forms, as well as before the interview, that they could withdraw from the study at any time.

Interviews

The interview schedule (Appendix 7) took into consideration the barriers and facilitators emphasized in previous literature, such as the work by Bosco *et al.,* 2020. Initial drafts of the interview schedule were developed by the research team and reviewed with a relevant stakeholder from a South Asian community group. Feedback was gathered on the relevance and cultural appropriateness of the questions for the target population. After discussing feedback from the stakeholder and research team, it was decided to include questions that asked participants not only about their own perspectives but also about potential perspectives of others in their community. This approach aimed to facilitate deeper exploration of the topics and encourage more comprehensive sharing.

The interview questions focused on participants' knowledge and personal experiences with dementia, their attitudes toward lifestyle changes that might lower their risk of developing the condition, the sources they rely on for health-related advice, barriers and facilitators to following lifestyle related advice, and their perceptions of support from healthcare services. The interviews were conducted using a semi-structured format, allowing the interviewer flexibility to exercise discretion in asking questions and exploring relevant themes that emerged during the conversation. Participants were also given the opportunity to discuss any points or reflections which were not included in the interview schedule.

Analysis

The author transcribed the interviews verbatim, ensuring the removal of any personally identifiable information from the transcripts. The data was then analysed using thematic analysis, which allows for the identification, analysis and reporting of patterns within a data set and involves six key stages: familiarisation with the data; generation of initial codes; searching for themes from codes; reviewing themes; defining and naming themes; and, finally, conducting the write-up (Braun & Clarke, 2006; Braun & Clarke, 2013, Braun & Clarke, 2023). Thematic analysis is considered a flexible approach that can accommodate various theoretical and epistemological perspectives, making it suitable for both deductive and inductive forms of analysis.

The analysis process was facilitated by the use of NVivo (QSR International Pty Ltd., 2020). Multiple close readings of all the transcripts were conducted, with line-by-line coding utilized to develop an initial list of codes, then introducing new codes as necessary. Adhering to the recommended guidelines for enhancing credibility in qualitative psychological research (Elliott *et al.,* 1999), several measures were implemented. Firstly, a second rater independently coded two of the transcripts. After completing this process, both raters discussed their initial codes, and a consolidated list of codes was created. Subsequently, the codes were grouped together to form overarching themes and sub-themes.

To promote a collaborative approach and improve the representativeness of the study's results, respondent validation (Barker & Pistrang, 2005) was also employed. In May 2024, an initial summary of themes, sub-themes, and analysis were sent to interested participants for feedback. Participants were explicitly informed that providing feedback was completely optional. McKim (2023) suggests that in qualitative research, having participants review and provide input on the drafted research findings and how their experiences are presented, rather than just the raw transcripts, can be beneficial. Reviewing transcripts alone may be insufficient as participants cannot see how their stories are woven together and contextualized in the final product. Instead, McKim proposes involving participants as experts to review the drafted findings with quoted material, allowing them to ensure their experiences are accurately and ethically portrayed before publication. This approach aims to strengthen the researcher-participant relationship and enhance the validity of the qualitative analysis, which is why respondent validation was conducted in this manner in the current study. Three participants expressed an interest in reviewing the themes and analysis, and ultimately, one participant responded, affirming that she felt the analysis accurately represented her views.

Researcher perspective

Validity in qualitative analysis is enriched when researchers practice reflexivity by disclosing the contexts, experiences, and worldviews that inform how they conceptualize and engage with their data (Caelli, Ray & Mill, 2003). As an Irish woman in my early thirties conducting qualitative research with Indian participants on dementia, I recognize that my cultural background and identity inevitably shape the research process. My Western medical perspective on dementia may differ from the socio-cultural and spiritual frameworks through which Indian participants understand the condition. Moreover, my questions, communication style, and areas of emphasis during interviews are influenced by my own cultural lens and priorities. Throughout the process, I have strived to remain reflexive, acknowledging how my positionality impacts the framing of questions, data collection, and interpretation of findings. Regular supervision, peer discussions, and maintaining a research diary have facilitated critical self-reflection on potential biases or assumptions. My supervisor, who is British Indian, has also provided valuable insights which helped to ensure my analysis reflects a broader cultural understanding and is sensitive to the nuances of the participants' contexts. While being drawn to participants' narratives that resonated with my cultural understanding, I have consciously endeavoured to give equal value to all voices and experiences represented in the study.

Results

Participant characteristics

The study involved fifteen participants of Indian ethnicity residing in England, with a diverse representation of different ethnocultural identities. The sample had an average age of 43 years and was predominantly female. The vast majority of participants were married, and their religious affiliations included Hinduism, Islam, and Sikhism. Educational levels were high, with all participants having at least an undergraduate degree. A significant number of participants reported experiencing depression, a known risk factor for dementia. Although fewer individuals were affected, a notable minority also reported other risk factors like hypertension, smoking, and excessive alcohol consumption. A full summary of this information can be seen below in Table 3 below.

Table 3
Demographic characteristics of participants

	Count
Total Participants	15
Sex	
- Male	5
- Female	10
Age (years)	
- Mean 42.6	Standard deviation 3.2 Age range 40-50
Ethnicity / Ethnocultural Identity	
- Indian	10
- British Indian	3
- Gujarati	1
- British Asian: Gujarat	1
Marital Status	
- Married	14
- Single	1
Religion	
- Hindu	12
- Sikh	1
- Muslim	2
Highest Level of Education	
- Undergraduate degree	5
- Masters	10
Current Employment Status	
- Full time employment	9
- Part time employment	4
- Unemployed	1
- Full time parent	1
Health Conditions (Self-Reported Yes/No Responses)	

	Count
- Hypertension	4
- Obesity	3
- Depression	6
- Hearing loss	1
Lifestyle Factors (Self-Reported Yes/No Responses)	
- Smoker	3
- Regular alcohol consumer	4
- Engages in regular physical activity	7
- Regularly spends time with other people (family/friends)	12

Thematic Analysis

The study employed thematic analysis, adhering to the six-stage process outlined by Braun and Clarke (Braun & Clarke, 2006). The ontological stance adopted was critical realism. Critical realism holds that language shapes how we know and experience the world, while also acknowledging that tangible social and material structures and mechanisms underpin the phenomena we observe (Willig, 2013, Terry & Kayes, 2020). Critical realism acknowledges both the objective and subjective aspects of phenomena. This enables a more comprehensive understanding of complex psychological issues by considering the interplay between external factors and internal experiences. This approach acknowledges the influence of broader social and cultural factors on people's experiences and behaviours. This is particularly relevant when studying minority ethnic groups, whose views and practices may be shaped by their specific cultural backgrounds, traditions, and societal positioning.

Critical realists hold an ontological realist stance, assuming that while our data can provide some insights into reality, these insights cannot necessarily offer direct or unfiltered reflections, as they are filtered through both the subjective views of the research participants as well as the theoretical lenses and contexts of the researchers. For instance, when interviewing someone about their experience of depression, the participant may not fully grasp all the factors influencing their experience, for example the historical evolution of the depression concept itself (Harper, 2011). Consequently, the data alone may not explicitly reveal the driving forces, historical contexts, or political underpinnings that shape and maintain various structures and practices. Therefore, critical realists argue that researchers must move beyond the textual data and incorporate other forms of evidence, potentially drawing from interdisciplinary sources, to gain a more comprehensive understanding (Harper, 2011).

The coding and analysis process was guided by the overarching research question. The initial stage involved familiarizing oneself with the data by carefully reviewing the content and making preliminary notes. Subsequently, an inductive coding approach was utilized, wherein codes were derived directly from the data rather than relying on a pre-existing coding framework. The coding was conducted at semantic and latent levels, allowing mainly for the identification of explicit descriptions or experiences shared by participants, as well as some consideration of underlying beliefs or structures which might have shaped responses. This approach aligned well with the philosophical underpinnings of critical realism. Subsequently, themes were constructed by grouping related codes and their associated data excerpts. This process began with the establishment of candidate themes, which were then evaluated for their ability to coherently capture the essence of the data. Following this assessment, the themes were examined and finalized to confirm they accurately reflected the main patterns and interpretations within the dataset.

The analysis yielded three main themes and seven sub-themes derived from the data, shown below in Table 4. For further illustration, Appendix 8 contains an example extract from a transcript with applied coding, while Appendix 9 provides a sample of codes which were collated to form a sub-theme.

Table 4
Overview of themes and subthemes

Themes	Subthemes
1. Navigating the Complexities of Dementia Awareness and Discourse in South Asian Communities	1.1 Limited Dementia Awareness
	1.2 Dementia as a Normal Part of Aging
	1.3 Stigmatized Discourse on Dementia
2. Determinants of Healthy Lifestyle Engagement: Personal and Contextual Factors	2.1 Internal Factors Influencing Adoption of Healthy Lifestyle Behaviours
	2.2 Systemic and Cultural Factors Influencing Adoption of Healthy Lifestyle Behaviours
3. Diverse Perspectives on Health: Accessing Medical Relationships and Other Information Sources	3.1 Trustworthy Sources of Information and Support
	3.2 The Role of Language and Communication in Health Literacy

Themes

Theme One: Navigating the Complexities of Dementia Awareness and Discourse in South Asian Communities

1.1 Limited Dementia Awareness

While most participants could define dementia as a condition affecting memory, they believed many older people in their communities lacked this awareness, which they described as manifesting in various ways. Awareness of the causes of dementia was generally low amongst participants also. One participant noted that individuals may sense cognitive challenges in others without explicitly attributing them to dementia: "*Yeah, they might have seen something that's going wrong with their mind. But it wasn't narrowed down to dementia (P10)."* Unlike more recognized conditions like diabetes, dementia lacks a defined vernacular in some cultures, perhaps making it challenging for families to understand their experiences. The absence of a specific term for dementia in some South Asian languages accentuates the linguistic and cultural gaps in awareness. As one participant explained: "*So I think the best thing to drive this point home, I don't know the Tamil terminology for dementia. There's not a word that people use… I have rarely heard people talk about dementia"* (P10).

Dementia was understood as a new illness by two participants, while another reflected on their confusion about the differences between dementia and various other health conditions: "*There's a few. Parkinson's and dementia. There's like three or four, which seem quite similar. And I think when we all kind of like, you know, hear she's got that, he's got that, we're a bit confused about what exactly each of these diseases entail, how do they kind of differ?"* (P3). For one participant (P5), dementia was something they had never discussed or seen any cultural or media references to. Two participants spoke about teenagers they believed had dementia: *"Because I heard of my friend, see her daughter got dementia. Yeah, and she cannot do basic things. Know some of the things, yeah. According to her. Like if she's like 18 or 19, but her physically capabilities are like that six to seven years old"* (P2).

This overall limited awareness about dementia extended also to its potential causes. Though a few participants like P16 mentioned factors like *"stress, unhealthy lifestyle, alcohol, smoking, lack of physical activity*" (P16) and genetics (P9) playing a role, most participants either did not know what might cause dementia or felt there was nothing that could prevent it. The widespread lack of understanding about dementia, its symptoms, and its potential risk factors in some members of these communities suggests people may not be adopting health behaviours aimed at preventing or reducing dementia risk. However, most participants felt they and others would be open to receiving more information, as P10 said: *"I think if people are aware that they have a higher risk...and if they have been given advice at the right time, with the right data, then yeah, that would definitely make an impact. Yeah, I'm not sure if people are aware. This is an awareness issue*." The findings reveal a lack of awareness about dementia, its symptoms, and potential causes among most participants. When awareness of a condition and its risk factors is limited, it naturally follows that people are unlikely to adopt healthy lifestyle measures aimed at preventing or reducing their risk of developing that condition.

1.2 Dementia as a normal part of aging

The normalization of significant memory loss as a part of aging may significantly impact the recognition and proactive management of dementia. P1 offered insights highlighting generational gaps and the impact of limited education on understanding dementia. According to this participant, her grandparents attributed significant memory loss to a natural aging process, lacking awareness of dementia as a distinct condition. She explained, "*Definitely my grandparents didn't know because they didn't have the education, so they definitely never knew what dementia means. Or their neighbours... They felt that because of his age he had some inability to recall events. So he thought that it was just that, because he was getting older.*" A similar observation was provided by P13 who described a family member whose severe memory issues were considered normal: *"It's just like not bypassed but it's just like, ohh, he's aging. Don't worry. He'll remember you next time."*

The normalization of dementia as a part of aging was highlighted by another participant who suggests that a significant portion of the community views dementia as an ordinary outcome of getting older, lacking specific concerns about the condition: "*They consider it absolutely normal that as you grow, you may not have the same memory as you had, and it's a part of growing old, so there's nothing specific to worry about in dementia."* (P15). P17 echoed the sentiment that understanding of dementia in their community is intricately tied to old age, and therefore there is limited consideration for preventative measures: *"They don't have that understanding to that extent, at least not in my experience. So they always just associate dementia with old age. Yeah, it's just because they're old. That's about it, you know, not like how could we have prevented it? Or what could have been done better?"*

The normalization of dementia as a natural part of aging therefore posed significant barriers to implementing preventative lifestyle measures. As severe memory loss was perceived as an inevitable consequence of growing old, particularly amongst older generations, naturally most participant’s families did not see a need to implement lifestyle choices to aid in reducing their risk of developing the condition.

1.3 Stigmatized discourse on dementia

The discourse on dementia within these interviews revealed a sense of stigma surrounding the condition within some South Asian communities. Participants highlighted how the avoidance of the term dementia and a reluctance to openly discuss issues affecting mental or cognitive health stem from a lack of awareness and fear of societal judgments, particularly amongst older adults. P10 explored this phenomenon, attributing the concealment of dementia within families to concerns about their children’s prospects being negatively affected: "*The thing with Indian people is they worry about discussing mental health issues or brain health issues in their family with other people because they worry about getting branded, and that could affect their arranged marriage for the future generation."*

The contrast between openly discussing physical conditions like diabetes while shying away from mental health conversations was evident: "*Yeah, I mean they always talk about openly about all somebody having diabetes. I have BP, that kind of thing. And it's almost like common lingo. But they wouldn't say someone has dementia, someone has an anxiety disorder"* (P10). Participants P17 and P9 described a sense of shame, embarrassment, and fear of societal judgment surrounding memory loss and mental health challenges: "*The sense of unease, I would say shame, embarrassment is there*." (P17); "*Not being aware of what it is, and you know people are kind of… when it comes* *to mental health-related issues, people are kind of very cagey and protective… They all get labelled with one common thing right? That they're mad.*" (P9)

While some exceptions existed, like P16 expressing more accepting attitudes, the narratives predominantly highlighted the pervasive stigma and its impact on recognition, open conversations, and help-seeking behaviours. The identified cultural norms of avoiding mention of cognitive issues, rooted in fears of judgment and concerns over societal repercussions like marital prospects, created barriers to recognition and dialogue. Without the ability to have open conversations surrounding dementia as a health condition, there may be little space for disseminating advice about potential lifestyle factors that could reduce risk.

Theme Two: Determinants of Healthy Lifestyle Engagement: Personal and Contextual Factors

2.1 Internal factors influencing adopting of healthy lifestyle related behaviours

In the discourse of several participants, an emphasis was placed on internal barriers to adopting healthier habits, for example, the challenge of balancing enjoyment of life with the potential benefits of adopting healthier habits: *"We still got our health. So actually why wouldn't we want to enjoy our lives, we subscribe to that a little bit too much" (P11).* The struggle to prioritise exercise and healthier dietary options reveals a conflict between awareness and action: *"It’s the temptation of other things and fitting in with our lifestyle, which is making us, then maybe not take some of these things very seriously" (P11).*

P14 also introduced an element of willpower as a crucial determinant in making lifestyle adjustments. The participant emphasized her husband's decision to adopt a healthier diet after developing diabetes: *"He takes it [sugar] now in other forms, in the form of dates or something. So there's always a way out."* The emphasis is placed on the role of willpower in making conscious, healthier choices: *"20-25% of the population of people can be saved from not getting this if they are that disciplined with their willpower"* (P14). Another participant suggests that overcoming initial challenges leads to habitual changes if one is persistent enough: *"If you overcome that for a month or two or three months... it becomes like an inherent thing and it becomes your habit."* (P16)

Dietary habits emerged as a focal point in participants' discussions about health. One participant stressed the importance of controlling what one can, stating, *"I can control my diet, keep it balanced and varied. I am very particular about that"* (P10). Additionally, concerns about dietary patterns were highlighted, as several participants noted a cultural preference for certain foods which they did not always perceive as being healthy: "*Food wise, there's a very carb-heavy diet. I'm like this crazy person for asking where's the protein?"* (P10). These quotes underscore the perceived link between dietary choices and potential health outcomes.

Despite awareness of the impact of lifestyle choices on health and dementia risk, P11 noted the need for a triggering event, such as a family member's diagnosis, to prompt lifestyle changes: *"We would have to really make sure, and think let's stop because we're really concerned that we're going to get this thing*." P6 echoed this, suggesting that a lack of perceived personal susceptibility is a barrier to proactive measures: "*Some are OK, some accept new information, but others will say 'Ohh, that is not gonna happen, and blah blah blah, and some people have got overconfidence on them (laughs). Ohh, this is not gonna happen to me.*"

Participants generally were aware that adopting a healthy lifestyle could lead to a lesser risk of developing various conditions, but some acknowledged that this information does not necessarily lead to change: "*You can't tell people you need to exercise. You can't tell people you need to eat better because we all know it and we still don't do it"* (P13). Most participants who did adopt a healthy lifestyle did so to protect their health generally, rather than to specifically try to mitigate their risk of developing dementia: "*People are like you can't go wrong if you just keep drinking 3 litres of water, for example, or just eating really well. That can probably save you from like about 20 of these diseases and stuff like even if we don't know how you get dementia and stuff" (P3).* One interviewee discussed how incorporating cognitive activities into their routine might improve memory and reduce dementia risk: "*What are the things we might start thinking about to try and improve our memory... to train our mind to the best we can"* (P11).

Another participant noted that making lifestyle change is hard when people have busy lives but added that "*some people are lazy"* (P5). Another felt strongly that if people could be more disciplined from an early age, then dementia and other conditions could be prevented: "*See, dementia can be prevented. We all know, I mean. Straight away starts with your physical activity and diet. So there's a clear answer to this and I think more, more people should, you know, start this discipline in their life early, as early as 25, and yeah you can't just drop this" (P14).*

Overall, participants identified various internal factors influencing the adoption of healthy lifestyle behaviours, including balancing life enjoyment with health benefits, the role of discipline and willpower, the struggle to prioritize exercise and dietary changes, a tendency to respond to specific health events rather than preventive measures, and resistance to acknowledging personal susceptibility to conditions like dementia. These insights underscore the complexity of translating health awareness into consistent action. While the internal factors discussed (enjoyment vs. health, willpower, prioritizing exercise/diet, resistance to susceptibility) could potentially be influenced by external or systemic factors, the participants themselves framed these factors as being more within their personal control and individual agency.

2.2 Systemic and cultural factors influencing adopting of healthy lifestyle related behaviours

Cultural factors, gender norms and a lack of information were identified as more systemic obstacles to healthy lifestyle adoption, contributing to lower participation in physical activities, especially for women: "*And then the women have stigma about going into the gym, even wearing the swimsuit or a, you know, they might consider lifting weights or something as more what a man would do than what women would do. Older people think that lifting weights might break their bones, they might just do simple walking"* (P10). Another participant noted a similar tendency in her family, where exercising was not common and having pre-existing health conditions, experiencing pain, or not having a suitable environment to enjoy movement in served as additional barriers: *"They wouldn't do that. My mum would never go for a walk. I think because she's still in pain, she wouldn't really go and our pavement isn't even. So she finds it hard to walk, and most of them just find it hard to walk. So that's why they don't really, you wouldn't see them going for walks" (P3).*

Some participants perceived a cultural difference between Indian and white people in attitudes to, or normalization of exercise: *"So there's a big difference between I don't know* *what it is, motivation or like just laziness, I don't know, but generally you see too many people not getting on walks and stuff, whereas my neighbours like the older English ladies, they'll always just go down to the park have a little walk and come back"* (P3). Another participant provides a similar observation: "*I think also they are also less likely to go to go to the gym, you're less likely to see a South Asian person walking or swimming or whatever. More likely to see a Caucasian old person doing that."* (P10). Cultural and religious beliefs were woven into participants' discussions on lifestyle choices. Several participants noted a tendency for older adults in their community to become less independent in later life, comparing this to white communities where they felt that older adults needed to be more health conscious as their families might not care for them: "*Non South Asians have a different thinking that if I get to 80, I'm not gonna have anyone to look after me as I know no one to, you know, get me a cup of tea or do my washing",* adding: *"It's a different mentality, people are not as independent."* (P3)

The role of women as caregivers was noted by several participants, and how needing to be available for their families prevented them from taking time for themselves: "*What I have noticed from my mother-in-law and my mum. They would never say we're having bad days. They just carry on."* Another participant echoed this sentiment, highlighting how women who spend time looking after their households feel that the activity level inherent in these activity levels is enough: "*We have to look after the children. We have to look after the bills. We're doing everything we can. We're cooking this many times. You know, we're giving fresh food out. We're walking from here to XY and Z. So you know, that's good enough exercise. They're not thinking that, you know, to actually get exercise you need to raise your heart rate to a certain extent, or have that knowledge. But then they're* *just mobilizing that good enough, even though they might not be doing to the extent that is required for the actual prevention to happen and to be very frank with you, I'm a medical doctor myself by background and I don't do it so." (P17).*

Several participants highlighted financial barriers affecting people's ability to engage in healthy lifestyle related behaviours: "*I mean, the cleaner that was working for us, she's doing like cleaning and washing and stuff so how much time could she spend on, you know, focusing on her health?"* (P10). Other participants referenced the current cost of living crisis in the United Kingdom, and how families have to prioritize their essential needs: "*We are only spending on necessities. Yes. So in this situation, it becomes really difficult to have everything healthy and save money as well"* (P15); "*Possibly social and economic conditions. The majority of people might not be wealthy, especially in the 70-plus age group*" (P9).

Participants revealed an intersectionality of barriers, where cultural norms, gender roles, financial constraints, and pre-existing health conditions intersect and compound the challenges faced by individuals in adopting healthy lifestyle behaviours. Particularly for women of an older generation, societal expectations around caregiving and misconceptions about exercise may have reinforced more sedentary behaviours. The quotes suggest a normalization of sedentary behaviour within participant's communities, particularly among older adults.

Theme Three: Diverse Perspectives on Health: navigating medical relationships and other information sources

3.1 Trustworthy sources of information and support

Participants revealed diverse perspectives on trusted sources of health and lifestyle-related information and their experiences navigating relationships with medical professionals and systems. Some expressed a distinct lack of trust in U.K. medical professionals compared to those in their home countries. P10 emphasized, *"I myself don't trust the UK GPs as much. I trust the GPs I had in India*." This distrust stemmed from negative experiences, as P17 discussed the apprehension some community members feel about losing autonomy: "*They're always thinking, oh, If I say too much, then I'll be taken away, put up somewhere there or like, you know, something will happen to me that I don't want to happen.*" These deep-rooted fears made individuals reluctant to seek health advice or support from health services: "*They can see their families suffering and trying to look after them, but they will not ask for help as much.”*

P17's experience also shed light on the differential treatment faced by ethnic minorities in navigating healthcare systems, stating: "*I have firsthand seen that people are being treated differently*." Some participants also highlighted a cultural preference for providing family support over using health services: "*Because there are some people, then they say, oh, why should we bother people when we can look after our relatives, our families for ourselves. And why do we go to NHS and ask for the help?"* (P2). Here, "bother" conveys a reluctance to impose on external services or professionals, perhaps reflecting a cultural value of self-reliance and familial duty. This hesitance might also be influenced by previous negative experiences with healthcare professionals.

Generational and socioeconomic differences influenced how health information was accessed. P10 noted, *"So Indian people like us, we will probably, you know, find it from the Internet and talk to medical experts and yeah, that kind of thing. But if you talk about* *the previous generation people who moved in 1947 or who came here and don't have an education, they might find it from their peers, family groups and social networks."*

While some trusted the NHS generally, several participants highlighted how accessing GPs was difficult due to long waits, with care often falling short of expectations: *"Yes, you have to wait until one month, two months and then when you get to GP. They don't find out anything. Just give them paracetamol (P7)".* The presence of Indian doctors was seen by some as bridging cultural gaps. However, no participants in the study had received any information about memory, or how to reduce their risk of developing dementia from their medical providers, in contrast to some other conditions like diabetes: *"I'm not 100% sure with dementia. There are not any studies or anything like we have received yet" (P8).*

P10 emphasized the importance of culturally tailored dissemination of lifestyle advice: *"The worst way of sending information to somebody like an Indian person who doesn't know English is to send a letter from NHS...The second worst would be like a white person coming and talking about dementia...It needs to be customized. It needs to be spread by people that people can trust and connect."* Community networks were noted as key information sources by many participants, as P13 stated, *"What we tend to do is we are constantly watching what's going on in India as well, so we would digest information coming from there as well."* P14 added, *"See information will only come through word of mouth, you know."*

Religious practices intersected with medical guidance for some. P3 described seeking advice from "religious doctors" on TV programs. P10 suggested utilizing places like gurdwaras and mosques to disseminate health information. P3 said, *"But that's more of a yeah, like a kind of religious thing. Which some people believe in as well...If they've got* *something really bad. Like cancer, for example, they're having treatment. But in addition, they want these kind of prayer things as well."*

P17 highlighted how age and cultural hierarchies influenced credibility when receiving lifestyle or health related information: *"And you're talking to your elderly patient who has come through of Southeast Asian background and you're trying to engage them in health promoting activities, they will go home and say hey, that doctor is young, they don't know anything about our culture...But on the same hand, if you have somebody coming from a religious perspective, even if they're younger, they seem to have a lot of power holding over them."*

For some participants, trusted sources of health and lifestyle related information were influenced by a distrust of U.K. medical professionals due to negative and discriminatory experiences, preferences for family caregiving over institutional support, generational and socioeconomic differences in how information is accessed, and the intersection of religious beliefs and practices with medical guidance, highlighting the need for culturally tailored dissemination of information and support.

3.2 The Role of Language and Communication in Health Literacy

The ability to communicate effectively in a shared language is a fundamental component of accessing and comprehending health information. Limited English proficiency posed a significant barrier for some participants’ family members, hindering their ability to obtain support, to access health related information, and to seek advice within the healthcare system generally, as highlighted by P17: "*And if I was not even speaking English, or my English is poor, that's even worse, you know the support you will get."*

While some participants noted positive experiences with personalized care in both NHS and private medical settings, challenges within the NHS were acknowledged, such as the limited time allocated during GP appointments. This time constraint can be particularly problematic for individuals with language barriers, who may require more time to effectively communicate their concerns and fully comprehend the information provided.

The frustration and dissatisfaction experienced by individuals with limited English proficiency is evident in P3's quote: "*So I think there's also a disappointment that in fact, you know, then you've had it here basically, cause like they won't treat you properly. And umm I think they feel like they get rushed as well. Maybe their English is not perfect and they just get like rushed and rushed in, rushed out, you know?".* The sense of being rushed during appointments exacerbates the challenge of effectively conveying their concerns and understanding the information provided, leading to a perception of inadequate care.

P13 notes how for people, overcoming these language barriers means seeking health and lifestyle related information from their countries of origin becomes necessary: "*It's like even through the NHS, we might not be getting all the information we require and the language barrier being there because we all come from Africa and India".* By accessing information in their native languages, individuals attempt to bridge the gap created by linguistic differences and ensure a more comprehensive understanding of health-related matters.

The consequences of language barriers in healthcare settings was illustrated by P17 who spoke about a friend's difficulty in securing appropriate care for their family member: "*Instantly, like I recognize, like there's a massive barrier to her accessing the service* *because there is nobody speaking her language. So if he leaves her there, she will have nobody to communicate with essentially."* The inability to communicate in a shared language can completely obstruct an individual's access to services and leave them feeling isolated and unable to articulate their needs or understand the information provided. These experiences are likely to shape a person’s openness and ability to seek advice about their memory or health from medical professionals.

P8 highlights the generational divide in language proficiency, with younger generations being more proficient in English while older generations may struggle with understanding health information presented solely in English: "*Probably it's a language barrier as well because like the new generation they are OK, they do understand English better, but the old generation who speaks particular like Hindi, Gujarati or Punjabi language. They might not understand what the exact scenario is if you have only whatever information. In multi-language that would be appropriate."* The suggestion of providing multilingual resources is offered as a potential solution to address this language barrier and ensure that health information is accessible to individuals with diverse linguistic backgrounds. These narratives underscore the profound impact of language barriers in healthcare, revealing a crucial need for more inclusive communication strategies that accommodate the linguistic diversity of patients to ensure equitable access to health information.

Discussion

The aim of this study was to better understand the attitudes of cognitively healthy adults in ethnic minority communities towards lifestyle recommendations for dementia risk-reduction. This was important because dementia is a major public health issue, and research has shown that South Asian people are more likely to develop dementia and may have less knowledge about the condition compared to other groups in the United Kingdom (Blakemore *et al.,* 2018). By exploring attitudes within these communities, the study could provide insights to inform culturally appropriate dementia prevention strategies and educational initiatives.

The themes outlined in this study highlight the multifaceted barriers and facilitators that influence the adoption of dementia-related lifestyle changes within South Asian communities in the United Kingdom. Theme one "Navigating the Complexities of Dementia Awareness and Discourse in South Asian Communities" highlighted limited dementia awareness, stigmatized discourse around the condition, and normalisation of memory loss. Stigma was associated with a diagnosis of dementia in other studies investigating the views of South Asian people (Bowes & Wilkinson, 2003; Mackenzie, 2006). This stigma around dementia may impede crucial conversations that could promote better understanding and supportive interventions.

Many participants indicated that particularly amongst the older generation, dementia is rarely understood as a distinct condition separate from normal aging. The absence of a specific term for dementia in some South Asian languages, as noted in Theme 1, may further accentuate the linguistic and cultural gaps contributing to this lack of awareness.

This normalization of memory loss as an inevitable part of getting older represents a significant obstacle to recognizing dementia's warning signs and adopting preventative lifestyle measures. It can also influence help seeking. This understanding of dementia as a normal part of older adulthood has also been found in other research studies (Parveen *et al.,* 2017; Johl, Patterson, & Pearson, 2016). One’s understanding of what causes a condition is crucial because it can shape perspectives on prevention strategies, approaches to managing the condition, and perceptions about the individual's ability to mitigate their chances of developing an illness (Hurt *et al.,* 2011).

A thematic synthesis conducted in 2021 revealed that some participants attributed their reluctance to acknowledge the personal relevance of dementia risk reduction to a fear of dementia itself and the stigma associated with aging (Curran *et al.,* 2021). Certain participants preferred to avoid thinking about topics that could potentially induce anxiety. The authors proposed that this avoidance behaviour could be exacerbated by gaps in knowledge, endorsement of myths portraying dementia as a "normal" part of aging, and scepticism regarding professional advice (Curran *et al.,* 2021). This aligns with the current study's findings under theme 1.

Theme 2, "Determinants of Healthy Lifestyle Engagement: Personal and Contextual Factors," revealed how gender norms, caregiving responsibilities, and social determinants like economic factors shaped attitudes and behaviours related to lifestyle choices like physical activity and diet. Individual factors like willpower, enjoyment of existing habits, and resistance to recognizing personal susceptibility also complicated the facilitation of positive lifestyle changes. However, it is important to note that individual agency exists within a broader systemic context that participants may not have explicitly recognized, and that a comprehensive approach requires looking at both individual and societal factors impacting lifestyle choices.

Participants highlighted the challenges women face in prioritizing self-care due to caregiving responsibilities and prevailing gender norms that may discourage physical activity. As other studies have shown, facilitators for exercise include well-being associated with physical activity (Kelly *et al.,* 2016), which may be impeded for some members of this community due to gender norms and caregiving responsibilities highlighted by participants. Participants also perceived cultural differences between South Asian and white communities in norms and attitudes towards physical activity, with exercise being less normalized within their own communities according to some accounts in Theme 2. Economic factors also emerged as potential barriers for those unable to afford lifestyle adjustments like healthier diets.

Theme 3, "Diverse Perspectives on Health: Navigating Medical Relationships and Other Information Sources," highlighted varying levels of trust in healthcare providers versus preferences for traditional/religious advisors. Language barriers, particularly for older generations with limited English proficiency, hindered access to health information and services. In other studies, younger adults more often knew more about risk factors than older adults (Giebel *et al.*, 2019). In another study, involving mainly white participants, scepticism about focusing on risk factors for dementia prevention was present for many, because they felt evidence was inconclusive, or did not differ from risk factors for any other health conditions such as diabetes (Bosco *et al.,* 2020).

Similarly in the present study, some participants were more focused on how lifestyle changes might affect their chances of developing other conditions. Participants suggested that culturally tailored messaging from trusted community figures could enhance health literacy more successfully than generic resources. An interesting finding from Theme 3 was how religious practices and cultural hierarchies intersected with receipt of medical guidance for some participants. This highlights how cultural factors can influence perceptions of credibility when receiving lifestyle or health-related information.

The data suggests that most participants were unaware of any specific links between lifestyle adjustments and dementia risk. While some participants displayed some understanding of potential risk factors like unhealthy diets, lack of exercise, smoking, and genetic predispositions, a sizeable number of participants felt that nothing could be done to prevent dementia. However, many participants showed an openness to learning more about dementia, given the right approaches. This shows a need to increase educational initiatives for these communities, with efforts also confronting the stigma surrounding dementia and other mental/cognitive health issues.

Theoretical and clinical implications

The findings from this study carry significant clinical and theoretical implications for professionals in clinical psychology as well as other health professionals, particularly those working to promote dementia risk reduction among ethnic minority populations. A fundamental implication is the need for clinicians to adopt a culturally sensitive approach when engaging with clients from diverse backgrounds. Understanding a specific community's beliefs, stigmas, and trusted sources of health information is crucial for building rapport and delivering culturally resonant care. Several studies (Regan, 2014;

Blakemore, 2018) have identified the lack of culturally appropriate services and accurately translated neuropsychological assessments tailored for South Asian populations as a significant shortcoming, a finding reinforced by many participants in the current study.

The necessity of incorporating cultural and linguistic elements into theoretical frameworks for understanding health behavior change is highlighted by these findings. Health promotion approaches have been criticized for placing excessive emphasis on individual lifestyle modifications while overlooking broader contextual factors and societal determinants of health outcomes (Golden & Earp, 2012). Traditional models may fail to fully account for the nuanced challenges and complexities faced by ethnic minority groups, such as stigma surrounding certain conditions, the normalization of symptoms, and language barriers. The data revealed a significant mistrust of healthcare services among some participants, stemming from negative experiences and cultural differences, representing a systemic barrier that will require concerted efforts to overcome.

The interplay between individual beliefs and broader socio-cultural influences that shape health-related decisions is emphasized by the study's findings. The socio-ecological model offers a useful lens for comprehending the interrelationships between personal, social, and environmental determinants of lifestyle behaviors through its integration of intrapersonal factors, cultural factors, organizational factors, physical environmental factors, and policy factors (McLeroy *et al.,* 1988). Promoting health advice in a culturally appropriate manner and addressing systemic and individual barriers to the implementation of healthy lifestyles could lead to overall improved health outcomes, not just in terms of dementia prevention.

Health literacy and effective communication are crucial in promoting awareness and facilitating the adoption of lifestyle changes. The results suggest that improving health literacy requires co-producing educational materials and resources in collaboration with community members and leaders to ensure cultural relevance. Engaging trusted figures within these communities, such as faith leaders, to disseminate information and host educational sessions can build credibility and trust. Training clinicians in religious/spiritual sensitivity and exploring ways to integrate faith leaders in psychoeducational efforts could also be beneficial.

The role of stigma and cultural taboos in shaping illness perceptions and care-seeking was a prominent theme in this study. These attitudes and behaviors could be further explored through theoretical lenses like the Health Belief Model (Becker, 1974), which considers how individuals construct representations of illnesses. According to this model, individuals are more inclined to adopt recommended preventive health behaviors when they see themselves as being susceptible to the condition, believe the condition is severe, recognize the benefits of acting, consider the barriers to be low, and have a sense of self-efficacy. Many themes highlighted in this study showed barriers to the adoption of this model. For example, memory loss was often associated with normal aging, and there existed a lack of understanding or awareness of the benefits of lifestyle changes for dementia risk reduction among many participants.

A thematic synthesis conducted in 2021 found that for general beliefs about dementia risk reduction to translate into specific behavioral intentions, it is crucial that individuals perceive such risk reduction as relevant to them and coming from a legitimate source (Curran *et al.,* 2021). Potential enablers to help individuals navigate these barriers include using trusted sources to disseminate information, ensuring that this information includes precise and positive messages, and providing support to help individuals make sense of the information and process the potential anxiety or stigma of being "at risk." Several participants in the current study noted that engaging with a known and trusted GP or a trusted community leader could increase their sense of trust in the advice given.

Clinical psychologists and other health professionals could play a crucial role in designing and implementing interventions that address these stigmas and create safe spaces for open discussions. Clinicians could consider facilitating community-based support groups or psychoeducational workshops. Collaborating with respected community leaders and institutions, as suggested by several participants in this study, could create spaces for open discussion of dementia. This approach has the potential to normalize conversations and disseminate practical guidance for lifestyle adjustments anchored in community values.

Psychoeducational interventions may be warranted to increase dementia literacy and counter the normalization of memory loss as an inherent part of aging. Clinical psychologists can play a vital role in designing and delivering educational programs that raise awareness while sensitively addressing cultural nuances and entrenched mindsets surrounding dementia within at-risk communities.

For clients with limited English proficiency, a significant linguistic barrier revealed in the findings, clinicians must prioritize effective communication methods. Utilizing multilingual staff or professional interpreters is essential for comprehensive assessment, psychoeducation, and treatment delivery. Furthermore, clinicians need to assess whether information is being understood coherently in patients whose conversational English might be strong, but whose understanding of more specific health-related information might differ. Failure to bridge language gaps could further exacerbate access disparities and deprive vulnerable groups of crucial preventative care. Additionally, it is important to have meaningful conversations with patients about the use of family interpreters, as some patients in the findings preferred this option. Ensuring that patients are comfortable with the chosen method of interpretation can enhance understanding and improve the overall quality of care.

Finally, the findings suggest a need for advocacy at systemic levels to increase the accessibility and cultural responsiveness of dementia care services and informational resources. Clinical and health psychologists should play an active role in consulting with healthcare institutions, policymakers, and community stakeholders. As noted by the Lancet Commission (2017), the prevention of dementia requires a multifaceted approach involving both policy measures and individual actions. Preventive efforts should begin early in life and continue throughout the lifespan, with both public health programs and individually tailored interventions necessary to address risk factors. Policy efforts should target high-risk groups, promoting increased social, cognitive, and physical activity, as well as vascular health.

Many risk factors are linked to inequalities, particularly affecting minority ethnic groups. Addressing these factors involves not only improved and targeted health promotion but also societal changes to improve living circumstances, such as creating environments that encourage physical activity and improving nutrition to reduce high blood pressure (Lancet Commission, 2017). The World Health Organization's Global Action Plan (2017) similarly recommends implementing campaigns that could potentially counteract misinformation. For example, it suggests designing both local and national campaigns tailored to specific populations (including migrant groups), utilizing creative and health-promoting messaging. In conclusion, addressing dementia risk reduction within ethnic minority populations requires an integrative approach that combines culturally sensitive clinical practices, tailored health education, effective multilingual communication strategies, systemic advocacy, and the promotion of preventative lifestyle measures to ensure accessible and responsive care.

Future directions for research

Capturing the perspectives of older adults and individuals with lower educational attainment could provide a more comprehensive understanding across diverse demographic segments within the South Asian diaspora. Future research could also explore the perspectives of individuals who have low levels of social contact, as very few participants in this study had this risk factor. Furthermore, studies could focus on developing, implementing, and evaluating the effectiveness of culturally tailored dementia awareness campaigns, educational programs, and lifestyle interventions specifically designed for South Asian communities. Designing and testing interventions that incorporate cultural values, appropriate language support, and trusted community networks could then be assessed for their impact on dementia knowledge, stigma reduction, and the intention to adopt preventive behaviours. Moreover, longitudinal studies are needed to track the long-term effectiveness of culturally tailored interventions on behaviour change and dementia risk reduction. These studies could provide insights into the sustainability of preventive measures and the evolution of community attitudes over time. Finally, as this study explored only the views of Indian participants, future research could focus on other South Asian groups to ensure a more inclusive and representative understanding of the diverse experiences and needs within the South Asian diaspora.

Strengths and limitations

This study provides valuable insights into the perspectives of a demographic that is underrepresented in dementia and health research. The qualitative methodology allowed for an in-depth exploration of the complex interplay between cultural factors, beliefs, and attitudes towards dementia risk and lifestyle behaviours. The credibility checks employed, such as having a second independent coder and seeking respondent validation from participants, enhance the trustworthiness of the findings (McKim, 2023).

In terms of limitations, despite efforts to enhance trustworthiness, the inherent subjectivity involved in qualitative analysis and the researchers' positionality may have influenced the interpretation of findings. The sample consisted entirely of university-educated individuals who spoke English. This may limit the transferability of findings to South Asian groups with lower educational attainment or significant language barriers. This was mitigated to some extent by seeking participant’s perceptions on the views and experiences of other members of their community. The average age of participants (43 years) may not fully capture the perspectives and experiences of older adults who may face different challenges related to dementia awareness and lifestyle changes. However, the sample did contain a relatively high number of participants who had experienced depression, which is one of the risk factors for dementia, as well as a notable minority of participants who were smokers and who had hypertension.

While the study was advertised to the broader South Asian community, having all participants identify as Indian could be viewed as both a strength and limitation. On the one hand, it allows for a more nuanced examination of the cultural perspectives specifically related to dementia and preventative health behaviours within the Indian community. However, a limitation is that the experiences captured may not be generalizable to other South Asian ethnic groups, such as Pakistani, Bangladeshi, or Sri Lankan populations, who may have different cultural influences shaping their attitudes towards dementia. Given the underrepresentation of these populations in the current study, there may be unique barriers or challenges in engaging and involving certain South Asian community subgroups in research on this and other topics. Even within the Indian diaspora, there is a great degree of diversity that the sample may not fully represent.

Conclusion

The aim of this study was to better understand the attitudes of cognitively healthy adults in ethnic minority communities towards lifestyle recommendations for dementia risk reduction. By exploring attitudes within these communities, the study could provide insights to inform culturally appropriate dementia prevention strategies and educational initiatives. The themes outlined in this study illuminate the multifaceted barriers and facilitators that influence the adoption of dementia-related lifestyle changes within Indian communities in the United Kingdom. Limited awareness and stigmatized discourse surrounding dementia were prominent, with many participants, particularly older adults, normalizing memory loss as a part of aging, which hindered the recognition of dementia's warning signs and adoption of preventative measures. Stigma, cultural norms, gender roles, and social determinants like economic constraints and caregiving responsibilities further influenced attitudes and behaviours.

Participants expressed varying levels of trust in healthcare providers, often preferring familiar doctors or traditional/religious advisors. Language barriers, particularly among older generations, impeded access to healthcare services and advice, while younger adults generally had better awareness of risk factors. Despite these barriers, there was openness to learning more about dementia, especially through culturally tailored messaging from trusted community figures.

The study underscores the need for healthcare professionals to integrate cultural beliefs, stigmas, and social determinants into dementia prevention strategies. Partnering with community leaders and trusted information sources can help normalize conversations around cognitive health and improve health literacy. Additionally, addressing systemic impediments such as financial difficulties and caregiving responsibilities is crucial for enabling individuals to adopt healthy lifestyle changes.

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Part 3: Critical Appraisal

Introduction

In this appraisal, I hope to critically examine the process of completing both the systematic review on palliative care for South Asian people in the United Kingdom, and the empirical study on understanding barriers and facilitators to dementia risk reduction behaviours among Indian populations. Throughout this reflection, I will strive to acknowledge the impact of my own position and preconceptions on how the study was conducted, how I dealt with challenges which emerged during the process, how I made methodological choices, as well as some further discussion on the strengths and weaknesses of the study and future directions for research.

Researcher's Positionality and Motivation

I am an Irish woman in my early thirties, about to complete my final year of training in Clinical Psychology at UCL. With several years of experience across mental health and psychology services, including a placement in psycho-oncology where I worked with people facing end-of-life, I was struck by the lack of emphasis on end-of-life issues during any psychology training I had completed. I had not been exposed to any research in this area prior to my placement and wondered why in my experience of our discipline which studies the entire lifespan, relatively little focus is placed on the experience of a dying person. This led to my decision to pursue a systematic review in this area. A frequent critique of psychological research is its focus on white, western, educated populations, and therefore when embarking on this project, another important value for me was trying to recruit a more diverse sample (Henrich *et al.,* 2010; Nielsen *et al.,* 2017).

Reflexivity

Reflexivity involves closely examining personal, methodological, and contextual factors that influence the research process. Critical reflexivity in research involves recognizing that knowledge creation is intertwined with political and cultural landscapes (Palaganas *et al.,* 2017). A researcher's positionality is shaped by factors like class, gender, ethnicity, race, alongside individual identities moulded by socio-economic and political circumstances, influencing the texts produced. For example, my Western medical dementia perspective may differ from the socio-cultural and spiritual frameworks through which Indian participants understand the condition. Moreover, my questions, communication style and areas of emphasis are influenced by my cultural lens. Introspection about the research process and acknowledging potential influences of personal values and perspectives on findings is essential for bolstering credibility in qualitative inquiry (Jootun *et al.,* 2009).

In some research approaches, researcher subjectivity is viewed not as problematic, but rather as an inherent part of the process (Olmos-Vega *et al.,* 2023). While early methods like grounded theory originally embraced bracketing (attempting to set aside pre-existing knowledge and views to remain neutral), this idea of completely neutralizing researcher influence has fallen out of favour among some qualitative researchers who see it as unattainable (Olmos-Vega *et al.,* 2023). Collaborative reflexivity highlights the value of researchers working alongside diverse teams and participants to question assumptions through dialogue, rather than reflexive practices occurring in isolation through reflective journals alone. Therefore, throughout the process I consulted with other researchers, and my supervisor, and for the empirical paper, I also shared the themes and analysis with interested participants. This was done not only to check for accuracy, but also to increase reflexivity.

Berger (2013) highlights researchers' tendencies to emphasize or avoid certain material, questions, and participant responses during interviews. As Willig (2001) also describes, researchers shape interviews through their choices of questions, conversation topics, and decisions to expand or avoid certain areas. When starting this project, I had hypothesized that many barriers to lifestyle changes would be highly systemic, such as poverty, healthcare access issues, and inequalities. With this in mind, it is possible my questions would lean more toward exploring those areas. Taking a self-reflexive stance was facilitated through keeping a research journal, reflective peer sessions, and discussions with my thesis supervisor. Through engaging in these methods, I became aware, for example, of my potential tendency to steer participants towards more systemic topics, and was able to ensure as far as possible that I gave equal weight to participants' accounts of individual factors shaping their lifestyle choices. I also noticed when selecting quotes to include in the write-up, that I was more naturally drawn to the narratives of participants who provided what seemed to me like richer or more detailed responses. While these responses may have been particularly insightful, becoming aware of this allowed me to ensure that the voices of participants who may have been less fluid in their accounts were also included and given due weight.

The thematic synthesis

This section discusses the benefits and limitations of conducting a qualitative thematic synthesis, and challenges and reflections on conducting the synthesis. Qualitative literature offers numerous advantages in understanding the multifaceted experiences of individuals receiving palliative care. Firstly, qualitative studies provide an in-depth exploration of patients' experiences, capturing the emotional, social, and psychological dimensions of their journey. Through often detailed descriptions, qualitative research facilitates a comprehensive understanding of the complexities involved in palliative care experiences, in some ways going beyond quantitative measures. Moreover, qualitative research prioritizes the voices and perspectives of patients, caregivers, and families, aligning with the principles of patient-centred care. By foregrounding the lived experiences of individuals, qualitative studies ensure that the synthesis of evidence remains grounded in the realities and needs of those receiving palliative care services.

Despite these advantages, adopting a qualitative-only approach in synthesizing literature also poses several challenges. Since qualitative research often involves small sample sizes and specific contexts, its generalizability to broader populations can be limited. The context-specific nature of qualitative studies may hinder the extrapolation of findings to different cultural or socio-economic contexts, raising questions about the applicability of synthesized evidence in varied settings. The absence of quantitative data may limit the comprehensiveness of the review, particularly in evaluating the quantitative impact of interventions or treatments on patients' experiences and outcomes.

While quality checklists are commonly used, it is important to note that their application does not inherently guarantee research quality or rigor (Kitto *et al.,* 2008). This is particularly true for tools like the CASP, which can only evaluate the information presented in the final published paper. Consequently, such tools may more accurately assess the quality of the write-up itself rather than the underlying research process and methodology. Due to the word limitations for most journals, I wondered whether some of the CASP criteria would have been clearer had I been able to access the original manuscripts, which may, for example, contain more detail on methodological choices. Despite the structured nature of the CASP framework, there is still room for subjective interpretation of the criteria and questions. Different reviewers may have varying perspectives and judgments, leading to inconsistencies in the appraisal of the same study. I acknowledge that how I rated items was subjective, which is a potential limitation of using such frameworks.

In this systematic review, stakeholders such as patients, caregivers, and clinicians were not directly involved in defining the scope of the review or interpreting the findings. This may have represented a missed opportunity to ensure the review addressed issues and areas of inquiry most relevant and meaningful to those directly impacted by palliative care services. However, the review heavily relied on direct quotes from service users and clinicians, aiming to ensure that their voices were adequately represented in the findings.

Difficulties which emerged during the process

One of the key difficulties which I encountered during the research was managing contact from non-eligible participants. After widely advertising the study through social media, community centres, and charitable organizations, I received an influx of email responses, many with similar writing styles. Many of these potential participants were unable to provide a UK-based phone number. While some individuals may have misread or misunderstood the advertisement, I wondered whether some were hoping to receive the financial incentive for participation despite not meeting the eligibility criteria. Suspecting some responses might not be genuine, I consulted with my supervisor. We realized that using a platform like Qualtrics could have enabled tracking multiple responses from the same IP address. To address this issue, I emailed these potential participants requesting a screening call, where I could remind them of the inclusion criteria, and provide the consent sheet, and participant information sheet. Ultimately, I required participants to have a screening call on their U.K. number to verify their eligibility.

One interview was conducted before implementing this screening process, and I suspected it might not have been genuine due to the participant's very non-specific speech about the U.K. After discussing with my supervisor, we decided to exclude this interview from the analysis. Another interview was excluded because the participant was not of South Asian ethnicity. This interview did not proceed fully as it became apparent early during the call that the person did not meet the criteria. It was difficult to end that interview prematurely, but was essential to ensure the integrity of the research.

Following my experience with non-genuine participants, I found several recently published papers documenting researchers' similar experiences (for example, Santinele *et al.,* 2024). While online advertising and recruitment methods increase the reach and potential diversity of samples, as well as offering convenience for participants, the rise of non-genuine participants was an issue I had not fully considered in advance of my study. While offering payment could potentially incentivize some participants to misrepresent their eligibility, research suggests that investigators should assess the risks of deception on a case-by-case basis (Gelinas *et al.,* 2018). Adopting a blanket policy prohibiting payment due to deception concerns would be an overly broad approach. Instead, researchers should carefully consider the potential for payment to increase enrolment deception for each specific study, weighing both the research integrity implications and potential safety risks to participants. I reflected, as the authors note, that payment serves as fair compensation for participants' time, effort, and acceptance of research-related burdens, helping to ensure that research participants are treated equitably in exchange for their invaluable contributions (Gelinas *et al.,* 2018). While online recruitment offers many advantages, my experience has taught me to approach it with more caution in the future, carefully considering measures to mitigate the risk of non-genuine participants.

Identifying qualitative research can also be challenging due to the lack of established techniques and consensus on systematic searching (Barnett-Page & Thomas, 2009). To address these challenges, a comprehensive search strategy was implemented, incorporating multiple databases, forward citation searching, reference list examination, and consultation with a librarian.

Another area of difficulty for me was considering the feasibility of implementing recommendations made in both sections of my research to improve services in the near future, given the strain and resource constraints currently faced by our national health service. While I firmly believe we should continuously strive to enhance the quality and accessibility of healthcare services and persistently seek out avenues for tangible improvements, I could not help but reflect on the prevailing political climate and its potential implications.

Rationale for Methodological and Epistemological Choices

This part of the discussion explores the choice to use thematic analysis procedures, and the benefits of incorporating critical realism to understand complex phenomena like dementia within specific cultural contexts. Braun and Clarke's step-by-step thematic analysis procedures, as outlined in their 2006 and 2013 works, are not intended to be a comprehensive methodology tied to specific epistemological or theoretical commitments. Instead, they offer a flexible, basic method of data analysis. These procedures can be adapted to align with various theoretical frameworks, ranging from those requiring more scientific descriptive coding to those embracing interpretive modes. While the procedures can be used as a standalone data analysis approach, they can also be incorporated into other methodologies (Finlay, 2021).

Thematic analysis was chosen above Interpretative Phenomenological Analysis, which tends to focus specifically on the detailed examination of individual lived experiences and often involves a smaller sample size. Thematic analysis seemed more suitable to broader participant group, as the goal was to generate common patterns and themes. Similarly, more social constructivist approaches like discourse analysis primarily focus on how language constructs social realities, which can limit its applicability when the research aims to explore broader experiential themes or patterns across data. This focus may also overlook other important aspects of participants' viewpoints and experiences that are not explicitly tied to language use.

Qualitative researchers generally fall into two categories: those adopting a scientific, objective approach that emphasizes systematic coding and representation of explicit data, and those adopting interpretivist, relativist perspectives that reject representational 'truth' in favour of uncovering deeper meanings through creative and reflexive methods (Finlay, 2021). However, most researchers likely find themselves somewhere in the middle, which I believe I do, creating analysis from a critical realist or constructivist epistemology that recognizes knowledge as co-constructed, and participants' stories as reflecting subjective perceptions rather than objective reality. These researchers may blend scientific rigor with more interpretative elements in their analysis (Finlay, 2021). Where this approach is taken, it should be made clear and justified, which I have aimed to do in this study (Braun & Clarke, 2023).

Willis (2023) describes how critical realism, seen through the lens of Bhaskarian Critical Realism (BCR), provides a more nuanced understanding of causality. BCR helps us realize that events occur due to the interplay of various factors and mechanisms, rather than a single direct cause. It posits that everything that happens results from the interaction of different structures and mechanisms, some of which may be hidden or inactive at times but can still influence events when the right conditions are met. BCR also emphasizes the need to consider people's thoughts, meanings, and cultures, which are real even if they cannot be directly observed.

Critical realism provides a valuable philosophical framework for this thematic analysis because it acknowledges that people's understandings and experiences of dementia are shaped by underlying structures. For example, a critical realist approach recognizes that Indian cultural beliefs, practices, and contexts have a tangible existence that impacts how dementia is conceptualized. Simultaneously, critical realism's epistemological relativism allows the researcher to explore how different groups within Indian society may have varied perspectives on dementia based on their unique situations and experiences. By adopting critical realism, the thematic analysis can go beyond merely describing Indian people's articulated understandings to theorize how broader factors like social conditions, healthcare systems, and lifestyle patterns may interact as generative mechanisms influencing dementia conceptualizations and risk perceptions.

When deciding on data collection methods, I considered the different approaches available to achieve the research aims. To guarantee sufficient recruitment and data collection to reach thematic saturation (Braun & Clarke, 2006), it was necessary to adopt a flexible recruitment strategy. This involved offering participants the choice of conducting interviews by telephone, online video, or in-person, accommodating participant preferences and allowing for representation from various regions across England. In the end, all participants opted for either phone or video interviews. While conducting sessions online and by phone may have impacted the quality of interactions positively or negatively, offering various communication methods respected participants' time and increased accessibility for this underrepresented group. In-person interviews could have yielded richer data, although there are no guarantees. The perception of anonymity in remote interviews may also have promoted openness.

While my initial aim for the systematic review and empirical paper was to study South Asian populations collectively, the final sample for the empirical research ended up consisting exclusively of educated, younger Indian participants, possibly due to snowball sampling effects. On one hand, having a sample from just a single ethnic group within the broader South Asian diaspora means perspectives from other populations like Pakistanis, Bangladeshis, Sri Lankans etc. were omitted. However, focusing specifically on an Indian sample can also offer many advantages, allowing for a more nuanced examination of views and experiences particular to the Indian cultural context and meaning that more precise conclusions and recommendations tailored to a key demographic within the Indian diaspora can be suggested.

Member checking

Member checking typically aims to control for or correct the researcher's subjective biases or misinterpretations. It is ethically valuable when researching marginalized groups, especially if the researchers are outsiders (Braun, & Clarke, 2023). However, the use of member checking is underpinned by assumptions that there is an accessible truth of participants' experiences that can be conveyed by minimizing researcher influence. An alternative is the concept of member reflections, which does not aim for exact verification or accessing reality. Instead, participants are offered the opportunity to reflect on the analysis, offering additional insights and generating further data on the topic, rather than validating a singular truth (Braun and Clarke, 2023). McKim (2023) suggests that in qualitative research, having participants review and provide input on the research findings and how their experiences are presented, rather than just the raw transcripts, can be beneficial. Reviewing transcripts alone may be insufficient since participants cannot see how their stories will be woven together and contextualized in the final product. Instead, she proposes involving participants as experts to review drafted findings with quoted material, allowing them to ensure their experiences are accurately and ethically portrayed before publication. This approach aims to strengthen the researcher-participant relationship and validity of the qualitative analysis which is why I approached member checking in this way.

Carlson (2010) delineates the significance of informing participants that transcripts and quotes aim to capture natural conversational language, which often lacks complete grammatical correctness. This acknowledgment is helpful during member checking processes, as participants might feel embarrassed about their conversational style or grammatical errors. Based on the above, I explained to participants that the quotes were intended to capture everyday speech. Participants in this study were allotted more than three weeks to conduct each member check if they were interested in taking part. This extended timeframe afforded participants the chance to review the researcher's interpretations, offer feedback on the accuracy of their portrayal in the study, and share any additional thoughts they deemed relevant. Out of the participants, three initially expressed an interest in providing feedback on the report, but only one participant ultimately responded, stating that she was satisfied with the report and would not change anything. While it would have been beneficial to get more responses, providing the option to give feedback hopefully provided a sense of collaboration, and it was helpful to have one participant review it. This approach demonstrates a commitment to transparency and open communication between the researcher and participants and underscores the importance of participant engagement, which can enhance the trustworthiness and credibility of a study's findings (DeCino & Waalkes, 2019).

Future directions for research

Efforts should be made to enhance the representation of minority groups in academic research across various domains, including end-of-life care and dementia studies. This is crucial to ensure that research findings are relevant, inclusive, and applicable to diverse populations. Furthermore, future research could delve deeper into the intersectionality of identities and how intersecting factors such as race, ethnicity, gender, sexuality, socioeconomic status, and cultural background shape individuals' unique experiences of end-of-life care. Conducting in-depth qualitative studies to understand how these intersecting identities influence perceptions, coping mechanisms, and support needs related to end-of-life care could provide valuable insights.

The review highlighted a lack of research focused on the involvement and utilization of psychology services in palliative care specifically for South Asian patients and families. To address this gap, further investigation is needed to identify specific cultural, linguistic, and systemic factors that hinder or promote the utilization of psychology services by South Asian individuals and their families in palliative care settings. Exploring the perspectives of clinical psychologists working with these communities could help understand challenges and potential strategies for improving access and engagement.

Additionally, as this study's empirical sample consisted predominantly of middle-aged educated individuals, conducting research that captures the views of older adults and those with lower educational attainment could provide a more comprehensive understanding across different demographic segments within the South Asian diaspora. Moreover, future studies could focus on developing, implementing, and evaluating the effectiveness of culturally-tailored dementia awareness campaigns, educational programs, and lifestyle interventions tailored specifically for South Asian communities. Designing and testing interventions that incorporate cultural values, communication styles, and trusted community networks could assess their impact on dementia knowledge, stigma reduction, and intention to adopt preventive behaviours.

Conclusion

In reflecting on the research process, I have come to further appreciate the importance of critical reflexivity throughout all stages of qualitative inquiry. As a Western-educated researcher examining culturally situated experiences, it was essential to continuously examine my own assumptions and lenses through which I approached the topics of palliative care and dementia risk reduction behaviours. Engaging in reflective practices like journaling, peer discussions, and supervisory dialogue allowed me to become aware of potential areas of influence, such as tendencies to emphasize certain narratives over others or steer participants towards systemic factors. I found the research very interesting and engaging, and enjoyed the opportunity to speak directly with participants about their perspectives and lived experiences.

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Appendices

Appendix 1: Search Strategy

Key concepts*	**Palliative care**	**Psychosocial**	**South Asian people**	**Living in the United Kingdom**
Alternative terms / synonyms	hospice, terminal, terminal care, terminally ill, critical illness, palliative, hospice, dying, end of life, advanced disease, life-limiting, life-threatening, death, bereavement, advanced care planning, home care services	Ethnicity, ethnic minorities, culture, culturally competent care, religion, beliefs, needs, experiences, barriers, facilitators	Asia, Asian, South Asia, South Asian, India, Indian, Pakistan, Pakistani, Bangladesh, Bangladeshi, Afghanistan, Afghan, Nepal, Nepalese, Sri Lanka, Sri Lankan, Bhutan, Bhutanese, Nepal, Nepalese, Maldives, Maldivian, SAARC	UK, United Kingdom, England, Wales, Scotland, Northern Ireland
Search terms with operators	(Palliative care OR hospice OR terminal OR "terminal care" OR "terminally ill" OR critical illness OR palliat* OR hospice* OR dying OR "end of life" OR "advanced disease" OR "life-limiting" OR "life-threatening" OR death OR bereavement	(psychosocial* OR psychosoc* OR ethnicity OR ethnic minorities OR culture OR culturally competent care OR religion OR beliefs OR needs OR experiences OR barriers OR facilitators)	(Asia OR Asian OR South Asia OR South Asian OR India OR Indian OR Pakistan OR Pakistani OR Bangladesh OR Bangladeshi OR Afghanistan OR Afghan OR Nepal OR Nepalese OR Sri Lanka OR Sri Lankan OR	(UK OR United Kingdom OR England OR Wales OR Scotland OR Northern Ireland)

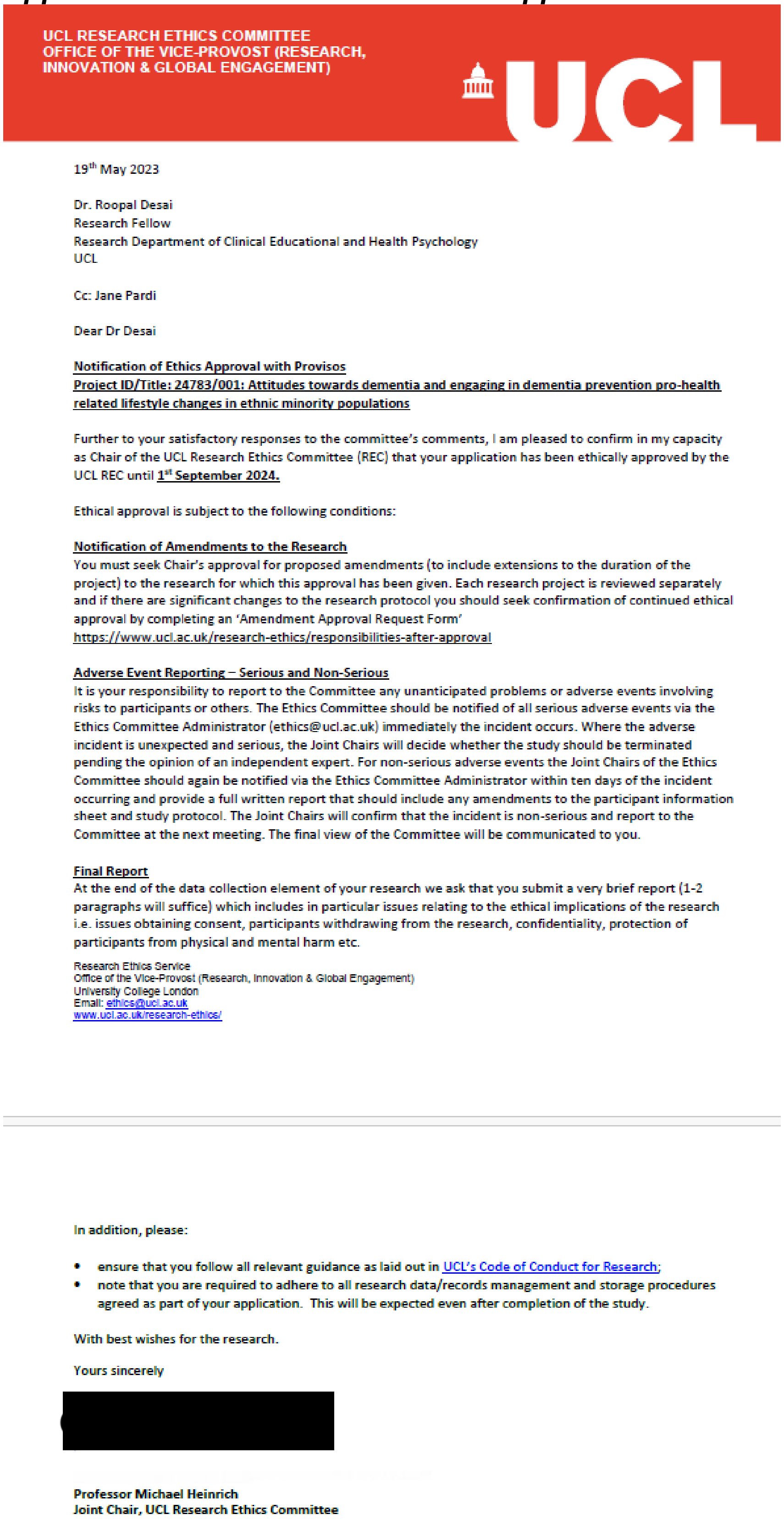
	OR advanced care planning OR home care services)		Bhutan OR Bhutanese OR Nepal OR Nepalese OR Maldives OR Maldivian)	
Databases searched: Scopus: one result Psychinfo: 79 results Medline: 286 Duplicates:62 (31)	**Date the searches took place:** 04/08/2023	**Limiters:** Results from 2003-present (August 2023) English language only		

Appendix 2: Quality Assessment Criteria (Critical Appraisal Skills Programme, 2018).

1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?
7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?

Note: Since Question 10 of the CASP Tool seeks a subjective assessment of the research's worth, rather than a definitive yes or no response, its values are not reflected in Table 1.

Appendix 3: Confirmation of ethical approval from UCL



UCL RESEARCH ETHICS COMMITTEE
OFFICE OF THE VICE-PROVOST (RESEARCH,
INNOVATION & GLOBAL ENGAGEMENT)

UCL

19th May 2023

Dr. Roopal Desai
Research Fellow
Research Department of Clinical Educational and Health Psychology
UCL

Cc: Jane Pardi

Dear Dr Desai

Notification of Ethics Approval with Provisos
Project ID/Title: 24783/001: Attitudes towards dementia and engaging in dementia prevention pro-health related lifestyle changes in ethnic minority populations

Further to your satisfactory responses to the committee's comments, I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your application has been ethically approved by the UCL REC until **1st September 2024.**

Ethical approval is subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'
https://www.ucl.ac.uk/research-ethics/responsibilities-after-approval

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Final Report
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

Research Ethics Service
Office of the Vice-Provost (Research, Innovation & Global Engagement)
University College London
Email: ethics@ucl.ac.uk
www.ucl.ac.uk/research-ethics/

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research;
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely

[redacted]

Professor Michael Heinrich
Joint Chair, UCL Research Ethics Committee

Appendix 4: Information Sheet

Research Department of Clinical,

Educational and Health Psychology

UNIVERSITY COLLEGE LONDON

What are the barriers and facilitators for ethnic minorities at risk of dementia engaging in pro-health related lifestyle changes?

PARTICIPANT INFORMATION SHEET

My name is Jane Pardi and I am a researcher from University College London. I would like to invite you to take part in this study.

You are being invited to take part in a research study as part of a Clinical Psychology Doctoral Thesis sponsored by University College London. Please read the below information carefully and discuss it with others if you wish. Please ask us if you need more information.

Why have I been chosen?
We are inviting people from South Asian communities to take part in an interview study about dementia.

You are eligible to take part if you:

- aged 40 or over
- are from a South Asian Ethnic background including: India, Pakistan, Bangladesh, Sri Lanka
- can communicate in English, or would be happy to be interviewed with an interpreter
- are able to provide written informed consent

You will not be eligible to take part if you:

- Have a diagnosis of dementia or cognitive impairment
- Experience sensory impairments to the extent that you would not be able to participate or engage in the interview.

Who is running this study?

This study is being organised by Jane Pardi and Dr. Roopal Desai at University College London who are sponsoring this research.

Why is this study being done?

We want to understand more about what helps or hinders people in making health related lifestyle changes which may lower their risk of dementia. We are interested in the views of people from South Asian backgrounds, as research shows that people from these groups are more likely to be diagnosed with dementia.

What does this study involve?

We will ask you to complete a short questionnaire about you (e.g. age, ethnicity). Then an audio-recorded interview will take place lasting approximately 60 minutes. You will be asked questions about what factors might influence you to make lifestyle changes which might lower your risk of developing dementia.

How will taking part impact me?

We do not think that taking part will involve any disadvantages or specific risks that would cause you any harm. Some questions may carry the risk of emotional distress, as they are personal questions in relation to your caring role. The research team will make every effort to be supportive in the unlikely event that participation in this study causes you harm. It is also important to remember that you can change your mind about taking part at any time. We hope that you will find the study interesting.

Where will this study take place?

If you agree to take part, a researcher will contact you to discuss how you would like to take part. This can be done face to face with a researcher or online/by phone.

What happens to my information?

All personal information about you during the study will be kept strictly confidential and destroyed at the end of the study. Data that we collect from you will be totally anonymised and be presented at conferences and published in scientific journals. We will follow the guidance from the General Data Protection Regulation (GDPR). You can ask for any data collected about you to be deleted at any time before the start of analysis, this means anytime before 01/02/2023

Data Protection Privacy Notice

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.United Kingdom. UCL's Data Protection can also be contacted at data-protection@ucl.ac.United Kingdom.

Your personal data will be processed for the purposes outlined in this notice.

The lawful basis that will be used to process your personal data are: 'Public task' for personal data and' Research purposes' for special category data.

Your personal data will be processed so long as it is required for the research project. We are able to anonymise the personal data you provide and will endeavour to minimise the processing of personal data wherever possible. All personal data will be destroyed following the completion of this study.

If you are concerned about how your personal data is being processed, please contact UCL in the first instance at data-protection@ucl.ac.United Kingdom. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: https://ico.org.United Kingdom/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

Who has reviewed this study?

This study has been ethically approved by the UCL REC: under the project ethics ID number 24783/001.

Whom can I contact for further information?
Jane Pardi
Research Department of Clinical Educational and Health Psychology
1-19 Torrington Place, London WC1E 7HB
Email: [redacted]United Kingdom

If you have any concerns or complaints about anything to do with this study, please contact:
Principal Investigator: Dr Roopal Desai
Research Department of Clinical Educational and Health Psychology
1-19 Torrington Place, London WC1E 7HB
Email: [redacted]United Kingdom

Appendix 5: Consent Sheet

Research Department
of Clinical, Educational
and Health Psychology
UNIVERSITY COLLEGE LONDON

What are the barriers and facilitators for ethnic minorities at risk of dementia engaging in pro-health related lifestyle changes?

This study has been approved by the Ethics Chair for the "Clinical Psychology" Research Department. Project ID number: 24783/001.

This study is being run by Dr Roopal Desai ([redacted]) and Jane Pardi ([redacted])

We would like to invite you to participate in this research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to read the following information carefully and discuss it with others if you wish. Please contact the researchers by email if anything is not clear, if you have questions, or if you would like more information about the study. You can also contact the researchers with any queries or concerns related to this study after completion.

It is important to note that you are only eligible for this study if you are over the age of 40 and do not have a diagnosis of cognitive impairment or dementia. We will ask you to complete a short questionnaire about you (e.g. age, ethnicity); you will only have to do this once. Then an audio-recorded, interview will take place lasting approximately 60 minutes where you will be asked questions about your understanding of dementia and your thoughts about how lifestyle factors such as exercise impact on dementia risk.

It is up to you to decide whether or not to take part. If you choose not to participate, you won't incur any penalties or lose any benefits to which you might have been entitled. If you do decide to take part, you will be asked to sign a consent form. Even after agreeing to take part, you can still withdraw at any time and without giving a reason. You can ask for any data collected about you to be deleted at any time before the start of analysis, this means any time before 29/06/023.

Data Protection Privacy Notice:

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.United Kingdom. UCL's research privacy notice can be read here. Your personal data will be processed for the purposes outlined in this notice. The lawful basis that will be used to process your personal data are: ‘Public task’ for personal data and’ Research purposes’ for special category data.

Whilst your data will be provided anonymously, at the point of data collection, your responses in the survey could, theoretically, be linked back to you via your Prolific ID. This is collected to enable your payment. After we have used the data for this purpose, this information will be deleted from the datafile. The data will subsequently be stored anonymously, such that your individual responses will not be traceable back to you.

If you wish to take part in this study, please tick ALL of the following boxes:

☐ I have read the information above and understand I can email the researchers with any questions. (1)

☐ I understand that my personal information will be used for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing. (2)

☐ I understand that all personal information will remain confidential and that my data gathered in this study will be stored anonymously and securely. It will not be possible to identify me in any publications. (3)

☐ I understand that my anonymised research data may be shared with, and used by, others for future research (no one will be able to identify you when these data are shared). (4)

☐ I understand that I am free to withdraw from the study without penalty if I so wish, simply by closing my browser. (5)

☐ I consent to take part in the study. (6)

Appendix 6: Demographic survey

Demographic questions	
Gender	
Age (years)	
Ethnicity /ethnocultural identity	
Marital status	
Religion	
Highest level of education	
Current employment status	
Mother-tongue and languages spoken	
Place of birth (if outside the UNITED KINGDOM then year of UNITED KINGDOM Entry)	
Dementia relevant health and lifestyle factors	
Have you been diagnosed with any of the following conditions?	
Hypertension (Yes/No)	
Obesity (Yes/No)	
Depression (Yes/No)	
Hearing loss (Yes/No)	
Other lifestyle related questions	
Are you a smoker? (Yes/No)	
Do you regularly consume alcohol? (Yes/No)	
Do you engage in regular physical activity? (Yes/No)	
Do you regularly spend time with other people, for example family or friends? (Yes/No)	

Appendix 7: Interview schedule

1. What is your understanding of dementia? Prompt: How did you come to this understanding?

2. Has anyone in your life had dementia? Prompt: how was this reacted to/understood?

3. Do you, or other people in your community, think that the risk of getting dementia can be

reduced in any way? Why/why not?

4. If you or people in your community were given information that their risk of getting dementia could

be reduced by making certain lifestyle changes, for example by exercising more, or not

smoking, do you think they might make these changes?

− If not, what do you think might make it difficult or unlikely for people to make these

changes?

-What would help people to make these changes?

Additional prompt: What specific support do you think would be most helpful in encouraging lifestyle changes?

5. Where do you think people in your community can find the most trustworthy information and

support about dementia?

6. Do you/people in your community feel supported with your health by services?

7. Is there anything else you'd like to share that I didn’t ask you today?

Appendix 8: Example of codes applied in a transcript excerpt

Interviewer: OK. And how do you think dementia is kind of understood or reacted to amongst people in your community?

P9: Ehm, it's not widely spoken about, I would say not. It's not really spoken of, discussed or people are not aware of dementia. (Codes: limited awareness, lack of education/awareness) It does get a mixed response from people. Suppose within my family, if my dad suddenly behaves in that way, I would understand that ok, you know something's going on, maybe dementia. But if the same person goes out and in the community and stops themselves and suddenly looks confused. People may not be able to, with that, they don't understand what's going on. And they would simply label them as mad. (Codes: limited awareness, stigma)

Interviewer: OK, so they would be labeled as maybe kind of mad or crazy?

P9: Yeah, it's a social label (Code: labelling, stigma).

Interviewer: Right. And you said that it's something maybe not really spoken about and I'm wondering if you have any idea if that's because people don't know a lot about it or is there something about maybe people being ashamed if someone in their family has it? Or something else?

P9: It's being ashamed and embarrassed. It's ashamed and embarrassed that there is something taboo to discuss mental health related issue, anything with your mind related, people are embarrassed and they would straight away think what would other people think (Codes: stigma, shame, mental/cognitive health)

Interviewer: Yeah, yeah.

P9: And I think that's what stops them seeking help when they really need it (Code: help-seeking barriers)

Interviewer: Right, right. So a sense of embarrassment, right? Or not wanting other people to know. That sounds really tough. And why do you think that it is potentially so shameful?

P9: I've been through similar things with depression and anxiety (Codes: depression, anxiety, personal experience of mental health) when it took me a few years to accept myself. (Code: self-acceptance). And even after accepting myself, that this is what the issue is, trying to avoid the help. (Codes: help-seeking barriers, self-acceptance). And that's purely… that's purely because of what would other people think and how they would react (Code: stigma). And I have first hand experience when I declared it at my workplace that this is what the issue is. (Code: personal experience of mental health) Some people are supportive, some people are behind your back would behave in a different way, although I must say right now people are more aware. (Codes: stigma, awareness of mental/cognitive health) There's more and more people are coming with, you know, admitting that yes, they got so and so issues. (Codes: mental health, awareness of mental/cognitive health).

Interviewer: Right, yeah.

P9: So it's a bit more open and people might not hesitate the way they used to in the past (Code: increased awareness of mental health).

Interviewer: And thank you for sharing. That's that sounds like it was really difficult for you and it's something that that you've really experienced and that that kind of stigma or shame about different kind of issues. And where do you think that sort of comes from? Why do you think it might be a source of sort of embarrassment to have a condition like dementia, for example?

P9: Not being aware of what it is, and you know people are kind of… when it comes to mental health related issues, people are kind of very cagey and protective. They wouldn't want to discuss anything with the… They all get labeled with one common things right? That they're mad. (Codes: mental health, labelling, stigma)

Interviewer: OK.

P9: That they're crazy people and things like that, you know? (Code: stigma). So no, the more people are aware of the condition itself. (Code: awareness). From dementia, Alzheimer's or depression, anxiety, panic disorder or schizophrenia, bipolar or anything, because the more people are aware and know there is help available and it's not what people think. (Codes: mental health conditions, awareness, help-seeking). It would help, but it's something that our parents, grandparents, the imaginary things they created in their head and then passed it over to their children. (Codes: generational differences, stigma) That's what it's kind of restricting people to be open and honest and seek help about it. (Codes: help-seeking barriers, stigma)

Interviewer: That makes sense. Yeah, that's really helpful. And what do people think causes dementia?

P9: Ohh I can't say about all the people. But I would say, say about myself, I would think that it's most likely to be in the hereditary or something to do with your DNA, you know if you have someone in your family. Then you're likely to get, but it's not the disease where you know you can catch a cold or. Or flu and things like that, this is. (Code: causes of dementia, heredity/genetics)

Appendix 9: Example of how codes formed a sub-theme

Code	**References**	**Files**	**Theme**	**Sub-theme**
Diet	9	6	Determinants of Healthy Lifestyle Engagement: Personal and Contextual Factors	Internal Factors Influencing Adoption of Healthy Lifestyle Behaviours
Exercise	14	7	Determinants of Healthy Lifestyle Engagement: Personal and Contextual Factors	Internal Factors Influencing Adoption of Healthy Lifestyle Behaviours
Lifestyle generally	17	10	Determinants of Healthy Lifestyle Engagement: Personal and Contextual Factors	Internal Factors Influencing Adoption of Healthy Lifestyle Behaviours
Motivation or personality as factors for lifestyle change	10	5	Determinants of Healthy Lifestyle Engagement: Personal and Contextual Factors	Internal Factors Influencing Adoption of Healthy Lifestyle Behaviours
Social activity or lack of	4	3	Determinants of Healthy Lifestyle Engagement: Personal and Contextual Factors	Internal Factors Influencing Adoption of Healthy Lifestyle Behaviours